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ABSTRACT

The report details the design, the implementation, and evaluation of three workshops on the role of the disability rights movement attended by 48 vocational rehabilitation (VR) state agency decision makers. Among the goals of the project listed were to make state VR agencies more familiar with the skills and potential of disabled self-advocacy organizations and to provide post-workshop technical assistance to both agencies and self-advocates. A questionnaire used to evaluate the workshops revealed that 86.9% of the respondents felt that materials distributed at the workshop would help them maintain closer ties with self-advocacy groups and the same percentage felt that there was a need to provide follow-up training to other agency personnel. The main portion of the report includes the following appendixes: an address, "Two Actors in Search of a Playwright" (F. Bowe); the trainers manual on "The Role of Self-Help Groups in Rehabilitation"; the results of the follow-up evaluation survey, copies of letters, and an annotated bibliography. (PHR)

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ROLE OF SELF-HELP ORGANIZATIONS IN VR WITH SEVERELY DISABLED INDIVIDUALS

FINAL REPORT GRANT #45-P-81285/3-01

Prepared by: Rita A. Varela

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Prepared by: Rita A. Varela

AMERICAN COALITION OF CITIZENS
WITH DISABILITIES, INC.

January 1979

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SIGNIFICANT REHABILITATION FINDINGS

- There are over two thousand organizations throughout the United States run for and by disabled people, or by parent groups. These self-advocates are eliminating architectural barriers, investigating conditions within custodial care institutions, teaching disabled citizens their rights, and shaping legislation. These groups are changing the options, the resources, and the rules available to rehabilitation professionals.

- ACCD's workshops on "The Role of Self-help Groups in Rehabilitation" gave VR officials an insiders' view of the disability rights movment. The workshops, by showing what self-advocacy groups are doing, demonstrated the skills and potential within the disabled community.

- Many of these groups are small and have neither paid staffs nor office space. In order to tap their resources, or to solicit their views on policy issues, agencies need to mount special outreach efforts. ACCD developed an Organizational Outreach form to enable rehabilitation professionals to log their contacts with advocacy groups. In a follow-up survey of VR workshop trainees, 86.9% of the respondents indicated that the form could help their agency maintain better communications with the self-advocacy organizations.

- 86.9% felt there was a need to provide follow-up training to other agency personnel.

ROLE OF SELF-HELP ORGANIZATIONS IN VR WITH SEVERELY DISABLED INDIVIDUALS

Final Report

Grant #45-P-8128/3-01

Project Director:
Rita A. Varela

Principal Investigator:
Frank G. Bowe, Ph. D.

American Coalition of Citizens with Disabilities, Inc.
1346 Connecticut Avenue, N. W.
Washington, D. C. 20036

January 1979

Covers research performed from September 1, 1977 to August 3, 1978

This study was supported in part by Grant #45-P-81285/3-01 from the Rehabilitation Services Administration, Office of Human Development, Department of Health, Education, and Welfare, Washington, D. C.

ROLE OF SELF-HELP ORGANIZATIONS IN VR WITH SEVERELY DISABLED INDIVIDUALS

Grant #45-P-81285/3-01 January 1979

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1346 Connecticut Avenne, N. W.
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Rehabilitation Services Administration
Office of Human Development
Department of Health, Education, and Welfare

AUTHOR'S ABSTRACT

Self-help groups--organizations run by disabled citizen or parent advocates--are a growing force in rehabilitation. In 1978 the American Coalition of Citizens with Disabilities (ACCD) received a short-term grant from the Rehabilitation Services Administration (RSA) to design, conduct, and evaluate a training program that would help rehabilitation officials learn how the skills and energy within these groups can be used to improve the VR system.

ACCD developed a workshop training module on "The Role of Self-Help Groups in Rehabilitation." The project staff conducted three regional workshops for VR state agency decision makers. The workshops trained 48 agency leaders from 42 state agencies (6 of the VR trainees were observers, and were sent to the workshops at agency expense).

Following the workshops, ACCD sponsored a Training for Trainers Conference to teach 18 self-help leaders from across the country how to replicate our project and offer that training experience to VR professionals within the state.

The module included three evaluation instruments: a pre-test/post-test; a participant evaluation questionnaire, and a follow-up survey which was administered six to eight weeks after each workshop.

In addition to the module and this final report, ACCD will be issuing two publications--Self-Help Groups in Rehabilitation, and Planning Effective Advocacy Programs--as well as other monographs and articles geared towards utilization by the Coalition's distinct publics: government officials, rehabilitation providers, and disabled people and their families.

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PREFACE

Self-help is not new in America. It is part of our ruggedness and central to our ingenuity. In a very real sense, though, cooperation and interdependence are equally vital to what we are as a nation.

As ACCD gathered material for its workshops on "The Role of Self-Help Groups in Rehabilitation," we saw those two strands in American culture blend. There would have been no project without the disabled self-advocates: some militant and angry; some eminently programmtic. It was they who challenged the status quo by saying that their community needed assertiveness training, independent living centers, barrier removal campaigns, and political organizing skills, and insisting that they could meet many of these needs themselves. Yet in doing their homework they paid tribute to the many theoreticians, rehabilitation professionals, engineers, and citizen advocates who pioneered the paths they now explored.

Throughout the project ACCD sought the counsel of professionals and disabled citizens across the country. They shared freely, and we are pleased to acknowledge them:

Joseph H. Owens, Executive Director, Council of State Administrators of Vacational Rehabilitation (CSAVR) and Mary M. Duncan, CSAVR, played a special role in this project. They helped us refine our objectives, track down research resources, and served as presenters during both the workshops and the Training for Trainers Conference.

Our advisory committee gave us more than suggestions. They gave us challenges that guided us throughout the project. We thank them all: E.

Russell Baxter, Commissioner, State Rehabilitation Services of Arkansas; Frederick A. Fay, Ph.D., Director of Research and Training, Tufts New England Medical Center (RT-7); Ann Ford, National Paraplegia Foundation; Judy Heumann, Deputy Director, Center for Independent Living, Berkeley, California; Craig Mills, Florida; Terrence O'Rourke, President, ACCD; Lawrence Pittinger, Department of Mental Health, Connecticut; Reese Robrahn, Executive Director, Indices, Falls Church, Virginia; and Phyllis Rubenfeld, Hunter College, New York.

We received strong support from Harold Shay, Director, RSA Division of Manpower Development, and from Dolores Watkins, VR Program Specialist, RSA Division of Manpower Development. We relied on their cooperation, and their experience as well.

The success of the workshops themselves was due largely to our consumer presenter and facilitators: Kate Hoffman, Boston Self-Help Center; Evelyn Stypula, Office of Supportive Services for Handicapped Students, Community College of Allegheny County, Pennsylvania; Jay Newman and members of Disabled in Action of Pennsylvania; Ellen Daly, Greater Milwaukee Area Chapter of the National Paraplegia Foundation; Audrey Benson, Scott Rostron, and members of the United Handicapped Federation of Minnesota; Lex Frieden, Research Director, New Options, Houston, Texas; Ralph Markward, Paralyzed Veterans Association, Zia Chapter, New Mexico; and Robert Funk, Thomas Manley, and members of the Center for Independent Living, Berkeley.

This project was a new venture for the Coalition. ACCD operated as a team, and it was the dedication of the staff that kept this project targeted towards excellence: Jan Corinne Saunders, ACCD Office Manager; Charles (Toby) McCoy, Admin. Assistant; Rose Ann Jackson, Administrative Secretary; Marcia Miller, Secretary-Interpreter; Ted Brosnan, ACCD's Management Training Consultant; and Bernard Glazer, ACCD's Accountant.

INTRODUCTION

> *Our goal was as ambitious as the need was great. But when Charles Donelly, a member of Pennsylvania's Disabled in Action, rose at the conclusion of the first workshop and said, "I think we've all learned something about each other in the last two days, and I think things will be a lot easier in the future because of it", we knew we had done a good job.*

Self-help groups--organizations run for and by disabled persons or parent advocates--are a growing force in rehabilitation. Their programs give disabled people new skills, more information, and a richer sense of self-worth, and their clout is being felt in state legislatures and Congress. Since many of the people in the self-help movement are current or future rehabilitation clients, agencies must know about this stride toward equity.

In 1977, the American Coalition of Citizens with Disabilities sought a short-term training grant from the Rehabilitation Services Administration (RSA) to help meet the agencies' need to know. RSA's short-term training program enables persons who work in the Federal-State Vocational Rehabilitation (VR) agencies, as well as other professionals, to keep abreast of research developments and trends in service delivery.

ACCD brought a special vantage point to VR training. The Coalition has over 45 self-advocacy groups among its national, state and local members. Our staff has close, personal ties with the disabled people who are running independent living centers and peer counselling programs, and not only know their problems, but know these individuals as colleagues and friends. The Coalition is a change agent, whose advocacy work turns on research, training, and action:

TABLE 1

ACCD ADVOCACY TRIAD

/Research/ + /Training/ = /Action/ + /Change/

Training styled by Advocates = Advocacy styled Training

=

The goals that ACCD set for the project (and that we subsequently refined and included as objectives in our grant proposal) mirrored the philosophy of the advocacy triad:

Goals

- To make state VR agencies more familiar with the skills and potential of disabled self-advocacy organizations.
- To show state VR agencies how to develop partnerships with such groups and how to use the talents of self-advocates to improve services.
- To develop a module on "The Role of Self-Help Groups in Rehabilitation", together with appropriate evaluation instruments; present and test the module at three regional training workshops; and publish a training package with the module, the instruments, and the results.
- To provide post-workshop technical assistance to both agencies and self-advocate.

METHODS AND PROCEDURES

We talked with dozens of people, we read everything we could get, and we revised constantly.

Our first step was to convene an advisory committee of rehabilitation specialists and self-advocacy leaders. We spoke with each member by phone, sent them information on our goals and research activities, and held a day-long committee meeting in ACCD's Washington office.

The notion of equal partnerships between consumers and providers is new. Few providers realize how much disabled people can offer, and few disabled people believe providers are ready to see them as equals. Our advisory committee wrestled with the issue of how to further this alliance, and decided that the workshops should be directed to policy makers. The committee felt that if we trained field personnel before we presented our case to agency chiefs we would be raising expectations before securing commitment. ACCD agreed, and we began examining the policy implications of consumer involvement.

As our research mounted we realized that people had too many questions about the self-advocacy movement for us to rely exclusively on guest speakers. Rather, the information had to be assembled, outlined, and presented in lecture form. We also wanted trainees to take an active part in the workshop, to confront issues and debate solutions. Therefore, we developed a module with lectures, problem solving, role playing, and ample time for questions and answers.

ACCD's workshop module featured a variety of training techniques and materials geared both to experential learning and back home utilization.

a) Lectures: The lectures gave policy makers an important overview of how self-help groups function, of the legislative and regulatory history of consumer involvement in rehabilitation, and of the accomplishments of these groups in advocacy and service delivery.

b) Small Group Sessions: The lectures were interspersed with problem solving and role reversal exercises. We knew from our review of group dynamics literature that role playing can be a risk. Sometimes participants become too polite and the reversal fails. During our workshops we noticed that since VR trainees had an insider's view of bureaucracy, they protrayed unusually adept self-advocates. We later found ourselves cautioning them not to expect all consumers to be equally versed on the intricacies of the system. Despite these caveats, the role playing sessions served as a catalyst to learning. Many of the trainees said the exercise gave them a challenging and needed opportunity to see the world from the client's perspective. It is, indeed, difficult to imagine the workshops without those sessions.

c) Consumer involvement at the workshops: Our advisory committee wanted to see disabled citizens at the workshops--as presenters, facilitators, and observers. We offered two types of consumer presentations at each workshop. First, we invited a disabled leader to describe a model self-help project. These leaders talked about how they began the project, how they obtained their funding, how they negotiated with the system, and how that project had shaped their relationships with the disabled community.

Second, we invited members of a self-help organization to give a group presentation. Our host group for the eastern regional workshop was Disabled in Action (DIA) of Pennsylvania. DIA held a board meeting at the workshop, enabling VR trainees to see who attends self-help groups and what the members talk about. Our midwestern workshop featured a panel from the United Handicapped Federation (UHF) of Minnesota. UHF members discussed their efforts in transportation, VR, and the rights of sheltered workshop employees. In Berkeley, the site of our western workshop, representatives from the Center for Independent Living reviewed their experiences as peer counselors and legal advocates.

We selected people with disabilities of all natures to participate in the training sessions. Moreover, each workshop drew on the talents of citizens who were primarily local leaders, who had been part of self-advocacy organizations for ten, twenty, and in some cases, thirty years. We wanted to involve the kind of disabled advocates whom VR officials would be most likely to have to deal with.

d) Guide to Self-Help Groups and Advocacy Organization: One of our goals was to show the size and diversity of the disabled self-help movement in America and encourage VR agencies to establish alliances with this constituency. We therefore assembled lists of all peer-run groups known to us and prepared statewide Guides to Self-Help Groups and Advocacy Organizations. Though each state Guide included some organizations run by non-disabled (or, surrogate) advocates, its primary purpose was to highlight self-help organizations.

Most self-help groups are small and have neither a paid staff nor office space. Often they use the home of their president as a mailing address. When there is a change in officers the group's files may have to be moved and communication with the group may be temporarily disrupted. Our staff designed a special Organizational Outreach Form to facilitate contacts between agencies and self-help groups. The Form allows professionals to record changes in leadership and keep a log of the dates and types of communication they've had with each group.

The Guides also contained a description of self-help projects around the country. These "Profiles in Action" covered peer counselling, employment strategies, campaigns to remove architectural barriers, and more.

EVALUATION: ON-GOING AND SUMMATIVE

The advisory committee saw this project as the first step in a training continuum. We needed a lot of feedback, and used many compasses to test our course.

a) Ongoing Evaluation: ACCD's evaluation strategies were formal, informal, and above all comprehensive. For this effort to serve as a cornerstone for further training, we had to know how closely we were meeting our goals during each phase of the project. The workplan outlined in our proposal to RSA formed the framework for our on-going evaluation, and it served us well. We achieved all of our project objectives.

TABLE 2

PROJECT OBJECTIVES

Objective	Implementation
a. To develop detailed performance objectives for VR personnel to meet in the course of training and in post-workshop activities.	Development of "Need to Know" topics (See Table 3)
b. To prepare training modules designed to assist participants to reach these objectives.	Consultation with CSAVR advisory committee, rehabilitation specialists and self-advocates. Consultation and research led to development of workshop curriculum and instruments (i.e., module on "The Role of Self-Help Groups in Rehabilitation.")
c. To provide accurate assessment instruments which will evaluate trainee progress and workshop effectiveness.	Developed three instruments, each reflecting a different evaluation method. 1) information-based testing; 2) decision-based testing; and 3) behavior-based testing.

d. To implement three workshops for a maximum of 20 participants each to be chosen in consultation with RSA and CSAVR.	Conducted three regional workshops for a total of 42 VR trainees, and 6 observers, plus one Training for Trainers Conference for 18 self-advocacy leaders.
e. To evaluate the training.	On-going and summative evaluation. Results from summative evaluations included in appendix, along with letters from trainees.
f. To revise the materials and procedures as indicated by evaluation.	The first workshop served as a pilot test for the module. All of the revisions completed before the second workshop.
g. To schedule regional replication workshops.	Our Training for Trainers Conference taught self-advocacy leaders how to plan, conduct, and evaluate replication conferences. Several groups, such as the Boston Self-Help Center and the PVA Zia Chapter in New Mexico have subsequently obtained state VR funding for expanded self-help efforts.

Consultation was key not only to data gathering but to evaluation. The Council of State Administrator of Vocational Rehabilitation (CSAVR) gave us vital guidance on project priorities and helped us access much of the material we used for the lectures. ACCD also relied on advisory committee members, before, during and after the meeting. Lastly, we spoke with dozens of disabled citizens who were running self-help projects or serving on VR advisory boards. Those citizens, because of their front line experience, had the information we needed in order to present workshops that went beyond mere literature reviews and that examined the political, interpersonal, and financial forces within the self-advocacy movement.

b) Summative evaluation: ACCD used three summative evaluation methods for testing the workshop module and designed separate instruments for each.

1. Information-based testing: As we gathered the lecture materials we noted those topics which are most essential to self-advocate involvement in VR. We began referring to these as the "need to know" topics:

TABLE 3

NEED-TO-KNOW TOPICS

TOPIC	PRESENTATION
Charpter 25 of the Rehabilitation Services Manual	Lectures, Issue Guides
Varieties of Consumer Involvement	Lectures, Issue Guides, Presentations by self-advocates
Problems between self-advocates and providers	Role-playing, Lectures
How self-help groups can improve service delivery	Guide to Self-Help Groups and Advocacy Organizations, Lectures Presentations by self-advocates.

We then designed a multiple choice pre-test/post-test questionnaire. At the workshops we asked trainees to code the pre-tests and post-tests by writing their Social Security number on them. In this way we could preserve the anonymity of respondents yet assure that only paired questionnaires were tabulated.

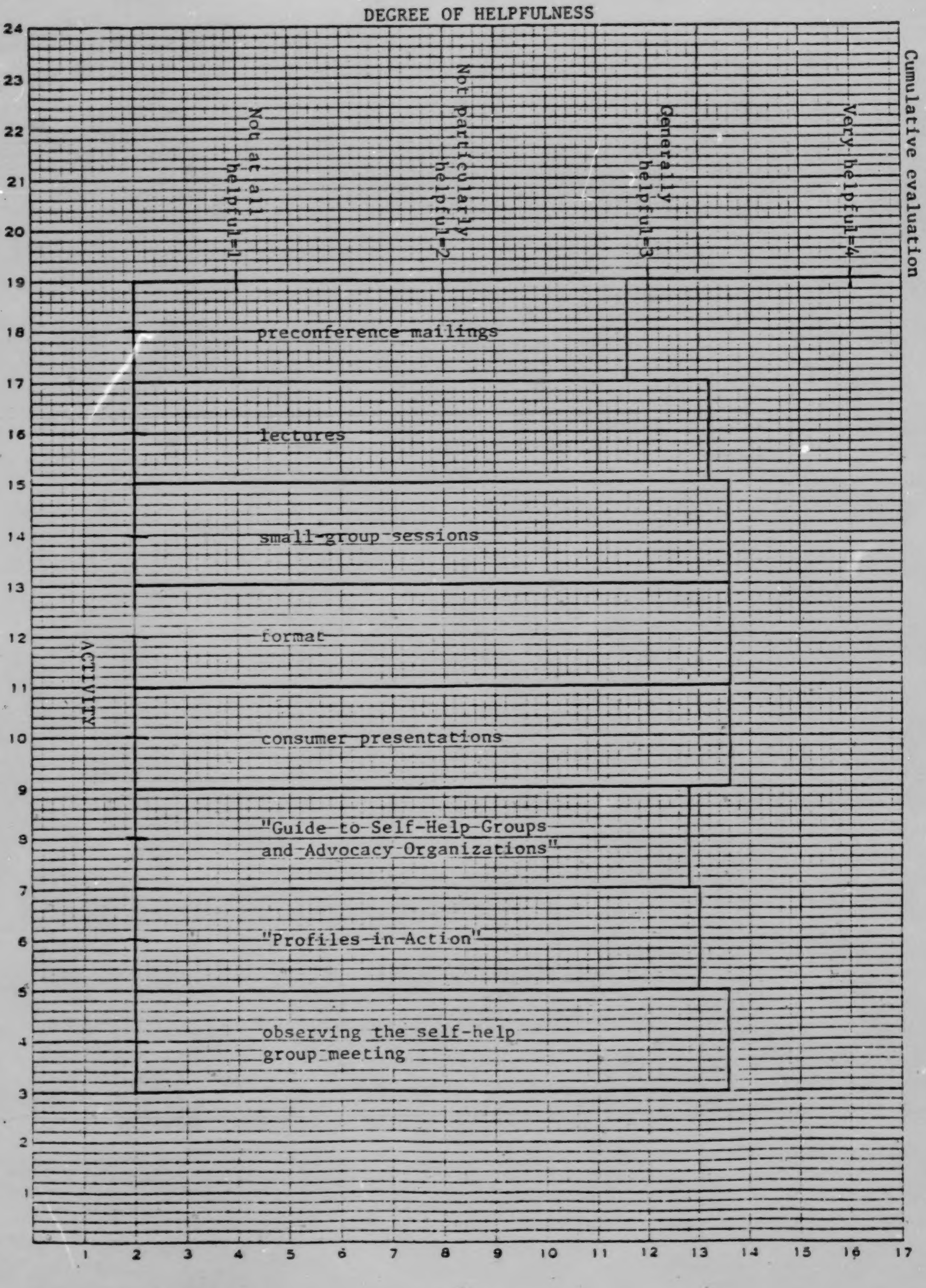
After the first workshop we did an item analysis to see which questions were answered incorrectly most often. As a result, we revised the questionnaire slightly and strengthened the lecture material. We also developed and distributed one-page Issue Guides that summarized each lecture.

2. Decision-based testing: Our second evaluation questionnaire tested the relevance of the workshop to the trainees' professional tasks. We asked each participant to rate each component of the workshop--lectures, presentations, and small group sessions--as either "very helpful," "generally helpful," "not particularly helpful," or "not at all helpful."

3. Behavior-based testing: Six to eight weeks after the workshops were mailed a follow-up questionnaire to participants to determine whether the training had led to changes in agency activities. The follow-up questionnaire was modeled after the Technical Evaluation Kit developed by the University of Oregon.

RESULTS

Thirty two general agencies and ten agencies serving blind citizens sent representatives. Five agencies sent observers as well, and paid the expenses of these individuals. Fourteen of the participants were state VR agency directors, and an additonal five were deputy or assistant directors.


DEGREE OF HELPFULNESS
Not at all helpful=1
Not particularly helpful=2
Generally helpful=3
Very helpful=4
Cumulative evaluation
ACTIVITY
preconference mailings
lectures
small-group sessions
format
consumer presentations
"Guide-to-Self-Help-Groups and-Advocacy-Organizations"
"Profiles-in-Action"
observing the self-help group meeting
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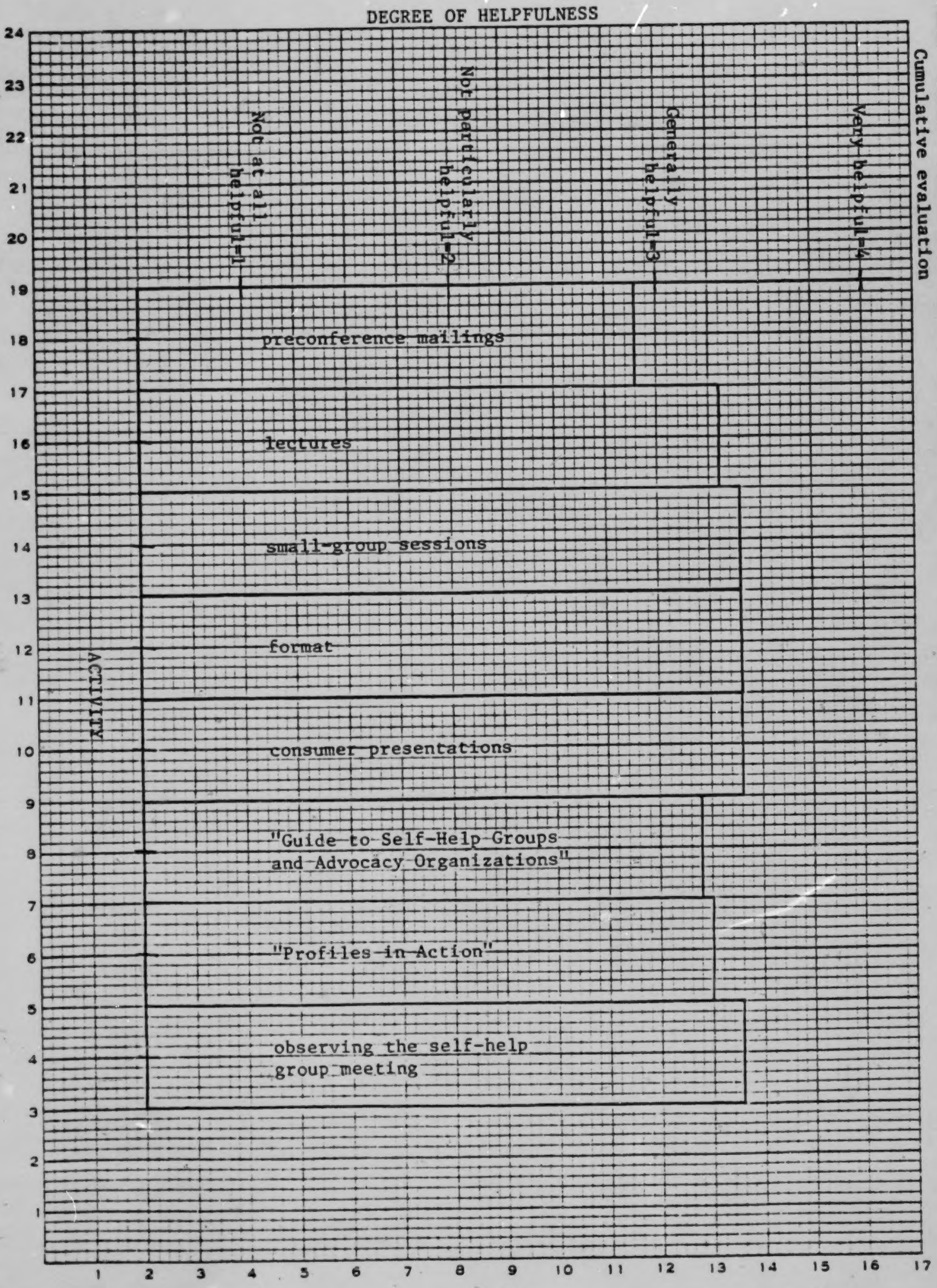
DEGREE OF HELPFULNESS
Cumulative evaluation
Not at all helpful=1
Not particularly helpful=2
Generally helpful=3
Very helpful=4
ACTIVITY
preconference mailings
lectures
small-group sessions
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consumer presentations
"Guide to Self-Help Groups and Advocacy Organizations"
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ACCD's workshops proved a dynamic vehicle for change. The participant evaluation sheets were overwhelmingly enthusiastic, as the cumulative bar graph indicates. Though the ratings were clearly positive, they do not convey the feelings or flavor of the workshop experience. Therefore, we are listing some of the comments that trainees included on their evaluation sheets:

- "Gave me a better understanding of consumer frustration with the bureaucratic process."
- "I was impressed by Frank Bowe's communication ability and humor, as well as by his knowledge of consumerism."
- "The workshop leaders did not see this as a state director's problem but rather as one that consumers and state agency staff must solve together."
- "An opportunity to 'break down barriers' between consumer and provider on a person-to-person basis."
- "Frank Bowe was excellent!"
- "Welcomed the exchange of knowledge with other agencies regarding consumerism."
- "Role reversal was an excellent exercise."
- "The timeframe kept the sessions moving at a good pace. Informative."

Finally, trainees became far more familiar with self-help groups, Chapter 25 of the Rehabilitation Services Manual, and other "need to know" topics. The average score on the pre-test for all three workshops was 71.1%. On the post-test, the score rose to 83.4%. But would the workshops have any lasting effect? Would agency people change their priorities or procedures?

ACCD's follow-up evaluation indicated that the Coalition's methodological advocacy triad paid off: Advocacy styled research and training does lead to action. The results from our follow-up survey are heartening.

We received a 54.7% return rate to the survey, a surprisingly high percentage for a mail-in questionnaire and itself an endorsement of ACCD's work. Of those, 74%

said the number of disabled citizens they spoke to about consumer involvement increased after the workshop. 91% said the materials distributed at the workshops helped them share the training experience with their colleagues, and 87% felt there was a need for follow-up training of field level VR personnel. In one project year, we made a good beginning.

TABLE 4

PROJECTS PRODUCTS--A SUMMARY

- Three regional workshops on "The Role of Self-Help Groups in Rehabilitation," and 50 statewide Guide to Self-Help Groups and Advocacy Organizations.
- One Training for Trainers Conference, and a Training for Trainers Manual. (Described below in our section on utilization).
- Two Monographs by Dr. Frank Bowe:
  a) "Approaches to Consumer Involvement", b) "Two Actors in Search of a Playwright." (See section on utilization).
- Two publications on consumer involvement:
  a) Self-Help Groups in Rehabilitation, by Rita A. Varela. (Expected publication date: February 11, 1979). Five thousand copies will be distributed free.
  b) Planning Effective Advocacy Programs. (Expected publication date: March 30, 1979). One thousand copies will be distributed free; additional copies will be available at a modest cost.
- A final report on "Role of Self-Help Organizations in VR with Severely Disabled Individuals" will be published and distributed free to rehabilitation officials and others associated with the project. Additional copies will be available at cost.

CONCLUSIONS AND RECOMMENDATIONS

Self-advocate involvement in rehabilitation is creative, cost-effective, good for the system, and good for the public at large. It is time to set priorities.

During the workshops we demonstrated the potential of self-help groups by showing what such groups have done. When groups mount campaigns to eliminate architectural barriers, the number of disabled people who are able to get to jobs increases. When groups help severely impaired citizens find barrier-free housing or obtain funds and technical assistance to modify inaccessible homes, the personal threat and public costs of institutionalization decreases. In these and in other ways, self-help groups are promoting individual freedom and improving the odds for successful rehabilitation outcomes. Our follow-up survey brought a clear mandate from VR professionals to continue offering training programs on the role of self-help groups in rehabilitation.

Yet throughout this project ACCD worked under the pressure of such limited resources that one conclusion has become inescable: to continue programs on self-advocacy at the current funding levels is not to further its cause but to stand still. Since the flow of research results is continuous, the need to synthesize it into new reports, instruments, and manuals never ends. Often the staff felt overwhelmed by the information explosion. We received far more requests for on-site technical assistance than we could provide. Precisely because rehabilitation funds are dangerously low, and because providers and consumers are realizing that the disabled community is an important, under utilized reservoir of energy, skill and commitment, projects such as ours create demands that cannot always be met.

In a time when policy makers are being forced to make harsh choices about which programs to support and which to cut back on, the fact that 87% of our trainees endorse the need for follow-up efforts in tremendously significant. It indicates that these officials believe that the self-advocacy movement is good for the system and good for the citizenry. This finding amounts to a plebicite. We asked state VR officials whether there was a need for follow-up training of field personnel, and their answer was a resounding "yes."

UTILIZATION PLAN

> *ACCD's workshops brought consumers closer to decision makers, and decision makers closer to the people they serve. On the state level, this responsibility should fall equally on self-advocacy groups and providers--yet neither need wait for the other to take the intiative.*

ACCD's project spoke about the partnerships between consumers and providers. Though the training module was geared to VR decision makers, we realized that in order to further this alliance our work had to serve the needs of both partners. Our utilization plan, therefore, relies on three strategies for change:

a) The Training for Trainers Conference (short-term strategy): VR officials told us that the kind of training experience we offered in our workshops should be available to field personnel. Since much of our material was culled from local self-help groups, we felt they should be the ones to replicate our project. We therefore convened a special Training for Trainers Conference, and invited 18 self-advocacy leaders from across the country to come and learn what we did and how we did it.

The module we developed for our workshops, including all our evaluation instruments, was issued in the form of a Training for Trainers Manual. That Manual is appended to this report. We are sending copies of this report to RSA officials, CSAVR, and other individuals involved in the project. ACCD will make additional copies available at cost.

b) "Self-Help Groups in Rehabilitation" and "Planning Effective Advocacy Programs" (mid-term strategy): Promoting consumer-provider alliances hinges on the merits of our case and on how widely we disseminate our information. Professionals need to know how consumer involvement has worked in various agencies, and need a document that they can discuss with colleagues. Concommitantly, the document must be distributed to a large number of self-advocates so that more people in the disabled community will begin exploring the need for closer alliances with providers.

ACCD has revised and expanded the material it used in its lectures and will be publishing a book entitled Self-Help Groups in Rehabilitation. 3,000 to 4,000 copies will be distributed free within two months of publication, and an additional 1,000 to 2,000 copies will be reserved and distributed free during future ACCD training activities. (Total: 5,000 copies will be distributed free).

New alliances will also depend on the effectiveness of self-advocacy groups. Telling group leaders about one specific series of workshops is not enough, for what we want to replicate is not just a project but a partnership. We will therefore be publishing a second book, Planning Effective Advocacy Programs, to give disabled consumers the management skills they need to become equal partners in rehabilitation and society. We will distribute 1,000 copies of this publication free, and additional copies will be available at a modest cost.

c) *"Approaches to Consumer Involvement"* (long-term strategy): Concurrent with the workshops, ACCD conducted a survey of consumer involvement in 42 state VR agencies. The survey told us a great deal about the role of disabled persons in VR policy making and gave us important clues to the training needs of both consumers and providers. Our new book, *Self-Help Groups in Rehabilitation*, includes a special report on the survey entitled "Approaches to Consumer Involvement," by Dr. Frank Bowe. The data, moreover, will help us design new modules keyed to today's needs and tomorrow's challenges.

Summary: The new training is in the wings. ACCD's forthcoming publications are at the printers. As noted, the first step of our utilization plan was to convene a Training for Trainers Conference. The Conference brought together self-advocates from across the country. Some were ACCD members and some were not, but each was a distinguished leader of the disability rights movement in his or her community. The Conference did not just review the workshop project. It offered the step-by-step training, in planning skills, grantsmanship skills, and management skills, that advocates would need in order to conduct replication workshops. We end this narrative by presenting a glimpse of that Conference, held on September 19, 1978, along with the full text of the *Manual*. The Conference began with Frank Bowe's keynote address, "Two Actors in Search of a Playwright."

APPENDIX A

AGENDA

ACCD TRAINING FOR TRAINERS CONFERENCE

Arlington Hyatt House
1325 Wilson Boulevard
Arlington, Virginia 22209

September 19 - 21, 1978

Tuesday, September 19, 1978

6:00 p.m.	Registration	
6:30	Welcome	Rita A. Varela Special Projects Manager American Coalition of Citizens with Disabilities (ACCD)
6:45	Introduction of Participants	
7:15	Keynote Address: Two Actors in Search of a Playwright	Dr. Frank G. Bowe Director, ACCD

Wednesday, September 20th

9:00 a.m.	Setting the Stage --- A New Partnership	Joseph H. Owens Executive Director Council of State Administrators of Vocational Rehabilitation
9:30	Questions and Answers, Discussion	
10:00	Skill Session: Potential to Actuality	
11:30	Questions and Answers, Discussions	
12:00	Luncheon Session	
12:45	Consumer Involvement in Rehabilitation --- The Tufts RT-7 Findings	Janet A. Minch Research Associate Tufts Rehabilitation Institute, RT-7
1:30	The Agency Perspective --- Training Needs, Purchase of Services, and Proposal Review	Vernon Hawkins Deputy Bureau Chief Social Rehabilitation Administration, Department of Human Resources

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Wednesday, September 20th

2:00 p.m.	Questions and Answers, Discussions	
2:30	Planning Session --- Strategies for Change	
4:00	Foundations Today --- Lecture and Slide Presentation	Mary Resnick, Librarian Washington Branch of the Foundation Center
4:45	Questions and Answer, Discussion	
Evening	On Your Own	

Thursday, September 21st

9:00 a.m.	Panel Discussion: Project Review --- All the Way Through	
	What Grant Reviewers Look For	Joseph LaRocca, Rehabilitation Consultant, The Urban Institute
	What is a Planner?	Ann Queen, Program Analyst Division of Planning, RSA
	Logistics of Conference Planning	Mary Duncan, Administrative Assistant, CSAVR
	Modern Workshop Techniques	Ted Brosnan, Rehabilitation and Training Consultant
	Moderator	Rita Varela
10:30	Questions and Answers, Discussion	
11:15	Closing Remarks	Rita Varela

TWO ACTORS IN SEARCH OF A PLAYWRIGHT [a]

Frank Bowe [b]

Good evening and welcome to ACCD's Training for Trainers Conference. I want to express to each of you my deepest thanks for taking time from your busy schedules to be with us in Washington for these few days. This Conference is a first for ACCD---and is one of the most important steps we have taken to date in our continuing efforts to effect more meaningful consumer involvement in rehabilitation. Your participation is an indication of your commitment to this objective, and I want to thank you for that.

I want to talk tonight about a partnership between consumers and providers, a partnership that resembles two actors in search of a playwright. I say that because disabled people and rehabilitation professionals have sought many of the same goals for the past six decades, but more often than not have sought them separately and independently. The relationship between consumers and providers has as often as not been characterized by mutual distrust, suspicion, and even antagonism. And this is strange, even tragic, because there is so much in common between the two, so many ways they can help each other. Tonight, we'll look at some of these ways.

Let me begin by sharing with you some of the avenues of cooperation we have found in ACCD itself over the past few years. I think it will be helpful for you because the experience we have had provides direct evidence that we as consumers can in fact work with and benefit from the assistance of rehabilitation professionals.

ACCD today is composed of 75 organizational members. Most of these, 45 in fact, are consumer-directed self-help groups representing virtually every category of disability. These groups have asked us to focus upon a number of top-priority goals: civil rights, special education, rehabilitation, and social security programs are prominent among these objectives. In our attempts to carry out the mandate we have been given, we have focussed upon monitoring of implementation of sections 501, 502, 503, and 504 of the Rehabilitation Act of 1973, as amended; we have attempted to facilitate the implementation of other sections of that act and to expand the work these statutory provisions authorize. We've tried to have an impact upon implementation of the Education for All Handicapped Children Act of 1975. And we have targetted many of our resources toward improving the social security disability insurance and the supplementary security income programs to eliminate the disincentives to employment and independence we find there.

Thirty of our members are professional associations concerned with disability. Among them are: Council of State Administrators of Vocational Rehabilitation (CSAVR), the organization bringing together the state directors of the 82 rehabilitation agencies nationwide; the National Rehabilitation Association (NRA), the major rehabilitation professional association; the Association of Rehabilitation Facilities (ARF), an organization of training and employment programs; and the National Association of Rehabilitation Research & Training Centers (NARRTC), the organization of 19 R&T centers sponsored with RSA research funds. These groups are "associate members" of ACCD. They are full partners in the work we do, but they do not enjoy voting privileges in the annual Delegate Council at which ACCD policy is determined. Associate members join primarily to express support for the work of the Coalition and to assist disabled people in reaching objectives we set for ourselves.

And they do. In each of the areas I've listed---civil rights, special education, social security, and of course rehabilitation---our associate members have demonstrated a deep respect for positions we have adopted and substantial support for us in our efforts to realize our goals. They have endorsed our work in other areas as well.

This is in fact not at all surprising. For the organizations concerned with disability and rehabilitation reflect the beliefs of their members that one of the highest callings our nation can response to is the call to do everything we know how to do to help people who have disabilities to overcome the limitations they face and become productive, self-sufficient, and independent citizens. Over the past few years, the organizations I've named have come to the conclusion that the realization of these goals, the response to the call, requires that consumers themselves determine what is in their best interests. Increasingly, these groups have looked to disabled people for leadership, for a sense of direction, for priorities. We in ACCD have tried to respond ---and to help these organizations do whatever it is they need to do to join their efforts with ours.

This is not to say that our strategies and theirs always coincide. It is not to say that no problems exist. It is not to say that an optimum partnership exists. But it is to say, and this is important, that both consumers and providers in ACCD recognize the commonality of interests and the primacy of disabled people in the setting of priortiies and goals. It is from this consensus that the partnership I have spoken about has emerged. And it is on this basis that both groups have helped each other more than either had expected when we began.

The partnership we have developed is a cooperation on the national level. It does not yet exist in equal measure on the state level. The critical questions are: Can it? And should it? Surely we must continue our advocacy roles on behalf of potential clients---and we will. These roles will bring us into conflict with state agencies from time to time. That is to be expected. But can we go beyond that? Let us look at these questions now.

ACCD recently surveyed the administrators of 42 state agencies to determine how consumer involvement mandated by Chapter 25 of the Rehabilitation Services Manual and the Rehabilitation Act of 1973 has been implemented.[c] We wanted to know what strategies the agencies were using, and which they perceived to be most effective. Then we asked them to rank order approaches toward enhanced consumer participation in agency policy making and service delivery. The findings are revealing. I want to focus now on those which have direct bearing upon the two questions I have posed.

We found, first of all, that virtually every agency was in fact involving consumers in its activities. That is important, and it represents a marked change over the situation that prevailed just five years ago.

The respondents in our survey expressed most confidence in personal contacts with consumers, rather than in such techniques as questionnaires and evaluation studies. The state directors want to expand their personal contact with disabled people. More than three-fourths of the agencies use one or more of these approaches: hosting meetings of consumers at the agency, attending meetings of consumers at organizational conventions and other settings, employment of disabled consultants, formal advisory bodies, and less formal correspondence, including telephone calls to consumers in the state.

We asked the administrators to tell us in what areas of agency activity consumer input was most valued. The range of activities is impressively broad. The directors reported seeking, and using, consumer advice in: assessing accessibility of agency facilities, recruitment of disabled employees for the agency, legislation and budget preparation, initiation of new programs including independent living, evaluation of agency services and program planning and development. Clearly, the input sought is not limited just to suggestions for improvements in the delivery of services to individual clients. Rather, over a wide variety of policy issues, the directors seek consumer input prior to making their decisions.

More than 60% of the agencies reported using paid consumer advisors as consultants---and rated this approach the most satisfactory they have used for consumer input. This suggests that the agencies are recognizing that just as psychologists and evaluators perform services of value to the agency for which compensation is just and appropriate, so too disabled people have information and services to offer which are deserving of compensation.

When we asked the administrators what they would like most to do to improve the quality of consumer input they receive, we were pleasantly surprised to discover that most believed that consumer involvement in the selection of consumer advisors is perhaps the most effective technique they could adopt. A majority expressed the conviction that this step, along with establishment of a central office liaison with consumer groups, would well serve both the agency and consumers themselves.

The directors also made several comments which are revealing of the problems and frustrations they have encountered in effecting improved consumer involvement. These are important for us to understand, because in these areas we can begin the rapproachment that will lead to better consumer-provider cooperation on the state level.

There was some support for the belief that consumer advisors, and likely disabled leaders more generally, could become markedly more effective in making the case in the public forum for rehabilitation programming. The directors feel that we have an interest in the extent to which the state invests in rehabilitation and that we can do more to express this interest to members of the general public, in the media, and before state legislatures.

The agency administrators felt that disabled people because of their contacts with a broad variety of state and local agencies and service programs could do much to enhance inter-agency cooperation. Rehabilitation, as you know, depends heavily upon such cooperation: it purchases services for clients from housing, transportation, medical, and other agencies. Inter-agency "red tape" represents one of the greatest frustrations the rehabilitation professionals face. They would like our help.

And they had a number of complaints about the extent to which we talk to each other about what the agency is doing and trying to do. Apparently, many of the "leaders" upon whom the agencies depend to "spread the word" about service availability, new programs, and policy issues talk only with other "leaders" and with others of the same disability. They are concerned that many of us devote too little time and energy to securing a genuine understanding of what it is that the agency is all about; we are, they often believe, too quick to criticize.

Finally, I want to add a few comments on observations expressed by the agency administrators we have trained over the past year in a series of workshops on self-help groups in rehabilitation. The participants in these workshops told us that they would like to know more about self-help groups in their state; almost invariably, they felt at a loss in realizing what resources these groups had to offer. The participants, too, wanted better information on how they could work more effectively with advocacy and self-help service groups.

These observations point to a number of conclusions important to all of us here tonight. Let me highlight a few:

(1) I believe it is fair to state that state agency officials generally are ready and willing to work with consumers to improve rehabilitation services. With an appropriate "script" for doing so, they are prepared to join us on the stage.

(2) We must do a much better job communicating to agency officials what our priorities, resources, and needs are. Too often, the agency representatives are unfamiliar with the work we are doing in our self-help groups. They need more accurate information about consumer beliefs and expectations with respect to agency policy and performance.

(3) We need to enhance our capabilities in public relations. This is true not only with respect to rehabilitation programming but to all of the areas with which we are concerned. The rehabilitation professionals we have surveyed and trained are telling us that they believe we can do more, that they are not seeing yet what they believe we could do in the way of setting the stage on the state level for improved services for disabled people.

(4) We need to talk to our "natural allies" including rehabilitation professionals so that action we take can be taken jointly and with more impact.

> Every indication is that rehabilitation agency officials will support us when we seek better access, removal of barriers, elimination of disincentives, improved educational opportunities, and other needed services.

These four conclusions are broad ones. Let us look now at some specific next steps we as self-help group representatives can take. Over the next two days we will be exploring in greater detail precisely how these next steps can be made.

First, I think, is self-assessment and evaluation. We need to look at our organizations with a critical yet appreciative eye. What is it we do best? What do we have to offer that the state agency (and other agencies and programs) need? We might find that we are very good at peer counseling, independent living services, outreach to potential rehabilitation clients, evaluation of the adequacy of services rendered to disabled people, training of professionals in human-service programs, advocacy for barrier removal, or any one or more of a host of other activities.

Second, is presentation and communication of these resources. We need to make potential "consumers" of our services aware of what it is we can best do---whether these consumers be purchasers such as rehabilitation agencies or clients who need our help. Few of the self-help organizations we have studied even have a brochure or other descriptive package outlining what they "do."

Third, is negotiation. Most self-help groups we are aware of are seriously resource-starved. Too few people are taking advantage of their services and too few agencies are purchasing these services on behalf of clients who need them. We need to identify sources of funding for our work and negotiate with these agencies for purchase of our services. The negotiation process involves meeting with agency officials, describing what it is we do, finding out what it is that the agency needs, mapping out a strategy combining the two, submitting a formal proposal outlining an approach to that strategy, and following up to secure the grant---and do the work.

Fourth, I believe, is offering what we naturally have aside from the specific services and activities we as organizations offer---our knowledge of disability, our contacts with disabled people, our first-hand appreciation of the priorities facing disabled citizens in our states and communities. We need to offer these kinds of knowledge and information to a group of people who want it---prominent among whom are rehabilitation professionals.

Over the next two days, we will be sharing with you what we have learned about these four steps within the context of a primary concern of state rehabilitation professionals---training of counselors on issues of concern to disabled people. We will be telling you what we did in the three workshops we have just held for state directors and their top policy aides, how we did it, and how you can do it on the state level. We will take you each step of the way---self-evaluation (to discover what it is you know that agency personnel need to learn), communication (how to present what you have so as to interest potential "consumers"), negotiation (how to prepare proposals and secure funding), and training (how to conduct the workshops themselves).

These skills are applicable not only to provision of short-term training in self-help groups to rehabilitation professionals but more generally to much of what you want to do in your efforts to increase the effectiveness of your organizations. The knowledge you will acquire over the next few days should prove helpful to you again and again as you proceed in your growth, assisting you to be more effective in meeting the needs of disabled people in your communities and states. And what you do will set an example for other self-help groups across the nation, helping them to evaluate their services, present their resources effectively, acquire the support they need to grow, and perform their activities more successfully.

What we want to do, then, is to equip you to play a role, to be an actor---on a stage and with a script of your own design. For the playwright both actors are seeking is within yourselves. You are both author and actor---in a play that urgently needs to be performed. So, go break a leg---let's do it!

Notes

[a] Keynote address to Training for Trainers Conference, 19-21 September 1978, Washington, D. C. Support for the conference was provided by the Rehabilitation Services Administration (Grant No. 45-P-81285/3-01).

[b] Dr. Bowe is Director of ACCD.

[c] Bowe, F. Approaches to Consumer Involvement. Mimeo, 1978.

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Bowe, F., Jacobi, J., & Wiseman, L. Coalition Building. Washington, D. C.: ACCD, 1978.

APPENDIX B

ACCD TRAINER'S MANUAL ON:
THE ROLE OF SELF-HELP GROUPS IN REHABILITATION

In This Manual . . .

Section I - Introduction

Blueprint

Section II - Minutes: ACCD Advisory Committee on Short-Term Training

Section III - Training Module: The Role of Self-Help Groups in Rehabilitation

Section IV - Evaluation Instruments and Results

Section V - Narratives from: *Guides to Self-Help Groups and Advocacy Organizations*

SECTION I

This section includes an orientation to project planning and implementation:

- Introduction
- Blueprint

INTRODUCTION

Commitment and Planning: A Process

This is a Training for Trainers Manual. In it we will describe a short-term training project to conduct workshops on "The Role of Self-Help Groups in Rehabilitation." These workshops were designed for state VR agencies decision-makers, and sought to familiarize them with the skills and potential of groups run by disabled persons. We will discuss concepts of planning, will give you a blueprint of what we did and how we did it, and will present all of the exercises, guides, and evaluation instruments used in the workshops. The Manual, therefore, gives you the tools you need to sponsor your own workshop --- and offers you planning which can be used in other projects as well.

A COMMITMENT

But first, a word about what the workshops meant to us. The American Coalition of Citizens with Disabilities is a national umbrella group of organizations. It includes both self-advocacy groups, such as Disabled In Action, and professional organizations, such as the Council of State Administrators of Vocational Rehabilitation. This mix of provider and peer groups is not only a purposive one, but reflects what's happening now. Increasingly, disabled citizens are speaking out on rehabilitation issues, and seeking a far larger role in shaping service delivery policies. In addition, a growing number of self-help groups are providing such services as peer counseling, information and referral, and training for independent living. Our short-term training project focused on these trends and their implications.

ACCD had two goals in sponsoring our workshops on "The Role of Self-Help Groups in Rehabilitation." The first was to draw attention to the various ways in which these groups are enhancing the rehabilitation prospects of disabled citizens: how such activities as barrier removal, employment advocacy, and peer support make it easier for disabled persons to fuction in society. The second was to strengthen the growing partnership between rehabilitation professionals and self-advocates. Our workshop accomplished the first goal. And, although we feel we made substantial strides towards the second, we are very conscious of the fact that that partnership, to be strengthened, requires on-going care and commitment. More than anything else, this Training for Trainers Manual is aimed at the second goal. It is aimed at you.

In reviewing the literature on research utilization, as well as on evaluation theory, we were sobered by the fact that the effects of short-term training projects can be quite transitory. Though a workshop may transmit vital information and offer a dramatic sense of renewal, the trainees returning to their agencies face the old rules, the old pressures, and the never-ending paper work. The literature tells us that implementation requires follow-up. To ensure that innovative concepts and procedures are integrated into a system, new trainers have to be trained, knowledge has to be shared through follow-up projects, and there must be a corps of post-training assistive personnel to answer question, offer support, and monitor utilization. It is our firm belief that the self-advocates themselves can accomplish those tasks.

As we noted, our workshops concerned self-help groups and rehabilitation. In analyzinag the issue of follow-up and implementation, we took another look at the development of the self-advocacy movement as a national force in order to see what it would tell us about change. We found that as self-advocates began speaking out on national rehabilitation policies, new relationships developed between professionals and consumers. More of them met. This introduction does not afford the space to examine that phenomenon. Nevertheless, the cross fertilization of policy and personal ties, as both --- or as either, for that matter --- a cause and a consequence in undeniable.

The alliance has not been an easy one. Self-advocates and providers do not always agree on priorities. Politicians and concerned citizens, furthermore, sometimes feel caught in the middle. Yet the perspective of slef-advocates --- their concerns, dissatisfactions, and dreams --- has influenced the dialogue on national rehabilitation issues. We find, mroeover, that local groups are having an increasing influence on state VR agencies. Self-advocacy groups throughout the country have received grants to sponsor peer counseling, 504 seminars, and counselor awareness training. We believe that workshops such as the one described in this Manual can strengthen alliances between self-advocates and providers. But we must remember that workshops do not create partnerships; relationships do.

What we are giving you, then, are the tools to put on your first workshop, along with some rules on planning, proposal writing, and evaluation which can be applied to a wide variety of projects. But we offer them with a cautionary note: the coalition-building does not stop there --- it only begins.

CONCEPTS IN PLANNING

One of the themes we discussed in our workshops concerned the difference in perspective between someone who works in a bureaucracy and someone who does not. People who work within highly complex structures are very conscious of rules and of the sequence of procedures. They are as concerned with how things are done as they are with what is done. These individuals work within an environment which places a high priority on planning.

There is, indeed, a science of planning; or, rather, a large number of theories striving to show the best way of doing things the best way. As specialists have sought to discover laws governing the science of planning, theories have become more academic and abstract, generating such phrases as "organizational matrix," "management by objectives," and "managerial grid." To the nonprofessional, such words can seem a bit intimidating. The issue we want to pose in this discussion is, what should you know about planning?

The issue is becoming very important to disabled self-advocates. As noted previously, a growing number of disabled citizens are starting self-groups, running peer support programs, participating in VR policy-making, and applying for grants. The success of these activitites is heavily influenced by the quality of the planning efforts which precede them. What is the relationship betwen quality of planning and management theories? How are they linked? They are linked by basic concepts of planning which become more useful as you become more familiar with them. Though there are no short-cuts to managerial proficiency, the tasks which have to be done will seem less awesome if you approach them with an attentiveness to basic planning concepts. We will talking about such concepts in these next few pages.

One of the clearest presentations of what the planning process is all about was developed by Frank Warren, technical coordinator of the Federal Programs Information and Assistance Project. In a training module designed for consumer organizations and developmental disabilities councils, Mr. Warren outlined a process he's termed "Action Planning."[1] Let's examine that outline:

> Part 1 - Reaching Basic Decisions
>
> A. The group identifies many needs, then lists them in order of importance and selects a goal from them.
>
> B. The group identifies problems that stand in the way of the goal, lists them in order of importance and translates them into objectives which must be met in order to reach the goal.
>
> Part 2 - Making Specific Plans
>
> C. The group maps strategies to meet each objective.

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[1] Frank Warren, Organizational Planning for Action, (DRAFT), Federal Programs Information and Assistance Project, Washington, DC, May 2, 1978, pp. 6-7. This outline is taken from a draft document, and is being reprinted with Mr. Warren's permission.

Part 2 - Continued

D. The group decides who will carry out each strategy, when it will be carried out, how the results will be reported to the group, and how strategy activity will be monitored.

Part 3 - Carrying Out the Action

E. Specific people carry out the action detailed in each strategy and report to the group.

F. If the objective is met in each case, the goal is achieved. If the objective is not met, the action planning cycle begins again at the strategy planning stage. This is continued until each objective is met and the goal is achieved.

The outline establishes certain categories: needs, goals, and objectives. With respect to our project, we can say that the need we identified was to increase self-advocate participation in vocational rehabilitation agencies. The goal was to hold workshops which would show VR decision-makers across the country that self-help groups had many skills which are valuable to the service delivery system. The objectives included such tasks as gathering information, finding accessible hotels, sending out invitations and preparing materials. In our next section, we'll present a more extensive discussion of the work involved in the project. It is interesting to note, however, that the concepts of "need" and "goal" are much broader than the concept of "objective." One person cannot increase self-advocate involvement in vocational rehabilitation agencies; one person can, however, book hotel space for a conference.

This distinction is central to the planning process. The "need" corresponds to what has to be done, whereas the "objectives" correspond to how things will be accomplished. Since objectives correspond to tasks, they can be assigned to people. That is, each task must be matched with a person, a deadline, and a method of reporting its status. Reporting is essential to the planning process; so essential, in fact, that it is often assumed instead of stated. Tasks which may seem easy during early planning sessions may turn out to be quite complex. Often, the speakers you want may be unavailable and the type of instructional material which you envision as being most helpful may not in fact exist. Someone will have to put it together from scattered reports and pamphlets. ACCD, for example, found that though they knew about the self-help movement because they knew the people who were in it; but that documentation on precisely what peer groups did and how they did it was fragmentary at best.

In this introduction we have offered some conceptual guidelines with which to think about the planning process. These concepts can also be seen as an attitude to planning. We've also talked about commitment, and have suggested that planning means translating goals into tasks. Our next section is quite different. In it we look at the planning of our short-term training project chronologically. That BLUEPRINT takes you on a step-by-step tour of what we did and how we did it.

Let's start at the beginning.

BLUEPRINT

Project Review - All the Way Through

In our introduction we tried to give you some of the fundamentals of planning. We stressed that successful planning is as much an attitude as it is a science. In the following discussion we will offer a blueprint of a project from its inception to its evaluation. As you read about its various stages you may want to bear in mind the approach towards planning we sketched earlier.

DEVELOPING A PROPOSAL

Writing a proposal is never the first step in a grant search process, it is the final one. You begin by examining your goals and resources, and then identifying funding sources concerned with those areas. This process is an interactive one: As you narrow down your funding sources you become more familiar with what agencies expect, and, concommitantly, you begin to clarify your ideas about what you can deliver. We will use the word "familiar" several times in this discussion. The professionalization of the self-advocacy community occurs with work and with time, and soon you will find that you are no longer in some "strange forest," for you'll begin to recognize the shape of the leaves and the paths leading to the streams.

During the early phases of a grant search, it is important for you to discuss your goals with peers, specialists, and, if possible, individuals in the targetted agencies. You'll generally find that these people are quite willing to hlep. It is easier for them to advise you before you submit a formal application than to have to process a poorly conceived grant proposal. Most successful grant seekers follow this approach, and it is the one adopted by ACCD in connection with our project.

In 1977, the Rehabilitation Services Administration sponsored a grant program to conduct short-term training for vocational rehabilitation agency personnel. Short-term refers to projects of one year or less. One of the topics for which proposals were requested was "The Role of Self-Help Groups in Rehabilitation." Clearly, this topic was within our field of interest, and concern.

Since its inception ACCD has sought to further the role of disabled citizens in shaping rehabilitation policies. This commitment mirrors the accomplishments of the self-advocacy movement. For years disabled citizens have been sponsoring conferences, publishing self-help guides, and providing various forms of peer support. However, because of inadequate transportation and architectural barriers, self-advocacy groups tend to be small, and few individuals outside of a given group's geographical area ever hear about its activities. The Coalition, because it includes 45 self-advocacy groups among its 75 organizations, not only knows about such projects but is in close touch with the people who run them.

Following the Request for Proposals (RFP's), ACCD began talking to both member groups and RSA officials. We reviewed what self-help groups had accomplished, and discussed possible ways of presenting this information during a series of regional workshops for VR personnel. The self-advocacy movement was growing. Disabled citizens across the country were serving on advisory committees, sponsoring independent living programs, and becoming politically active. Virtually everyone we spoke to felt that it was time to examine this phenomenon. The need had been explored and recognized. It was time to write a grant proposal.

Many people think of grant writing as a secret ritual masked in mysterious jargon. Actually, funding agencies have a clear interest in making the rules as simple as possible, and there is, in fact, a great deal of free information available to the novice grantsman. The key, again, is familiarization. Someone who is looking for a grant will be in a better position to understand the expectations of proposal reviewers if he or she begins to compare the RFP's of different agencies and foundations. RFP's and grant award announcements contain many of the so-called tips that one finds in over-priced fundraising manuals. These clues, however, often become obvious only after you've seen the way different funding agencies express their requirements and preferences. Since every agency and foundation has its own procedures, it is particularly important for you to understand the requirements of the one you plan to apply to. If there's anything you don't understand, don't guess --- ask questions.

The RSA regulations for the grant we were seeking required that state VR agencies be consulted in the development of a project, and that if more than one state VR agency is to be involved the project should be discussed with the Council of State Administrators of Vocational Rehabilitation. The standard procedure for soliciting CSAVR comment is through a preapplication to RSA. RSA will then forward selected proposals to CSAVR. ACCD was fortunate in having CSAVR support and assistance throughout the project.

WHAT GRANT REVIEWERS LOOK FOR

As we noted, the best way to learn what agencies look for is to become familiar with different RFP's and foundation announcements, and to ask questions. In time you will spot recurrent themes. These similarities will help you translate your goals into an actual grant proposal. Some of the ideas you should keep in mind as you write your proposal are:

- Is the need for the project clearly spelled out? Is it important?
- What people (target group) will it help or involve?
- Do the goals correspond to the methodology? That is, once you've listed the things you want to accomplish do you describe your plan for achieving each objective?
- What results do you expect?
- How will you evaluate (measure) your results? Will you be using tests? A survey? An advisory group? A combination of these, perhaps?
- Lastly, if you are in a wheelchair you already know that you're going to book conferences in accessible buildings; but grant reviewers do not know unless they are told. This information must be included in your proposal, along with accessibility assurances for persons who are blind (braille or tape), deaf (interpreters), or who may require attendant care.

Later in this Manual we will discuss in detail the evaluation instruments we used in our workshops. For now, however, it is important to distinguish between an evaluation instrument, such as a pre-test/ post-test questionnaire which measures how much trainees learned during the workshop, and the evaluation process. The evaluation process, much like the planning process, can be thought of as an attitude towards your work. In your planning process, you are charting out what you want to do and how you intend to do it. Your evaluation process is your way of monitoring your progress. Therefore, your evaluation process should be on-going; that is, it should parallel your planning efforts. Some of the measures you might use to check up on yourself are:

- Timelines --- are you meeting the deadlines you've set for yourself?
- Are you operating within your projected budget?
- Are you utilizing your consultants and advisory committees? They can be an important source of feedback.
- Lastly, what kind of feedback are you getting from your peers and colleagues?

Grant reviewers are well aware that unexpected events or problems can require major changes in projected plans. What these reviewers want to know is whether you are aware of that fact. In your grant proposal, therefore, you should describe your methods for on-going evaluation of your project.

ADVISORY GROUPS

Many, perhaps most, training, research, and demonstration projects use the services of either an advisory group or consultants. For our project, we assembled an advisory committee which included both rehabilitation specialists and self-advocacy leaders. We consulted with members of the committee several times before the formal meeting, as well as afterwards. Early in the project, members received copies of pre-meeting materials we had developed. In a separate mailing, we solicited their views concerning major issues of the role of self-help groups in rehabilitation. This mailing did not use a scientifically designed questionnaire but, rather, an informal feedback instrument which was also sent to a large number of professionals and self-advocates. The purpose of this informal survey was to identify priorities.

Following these mailings, we held telephone conferences with each of the committee members to discuss project goals and obtain input on developing an agenda for the m-eting. The minutes of the meeting itself are included in this Manual in order to provide a sense of the concerns and priorities expressed at the start of the project.

Advisory committees and consultants can add intellectual richness to a project. The tasks performed by those serving in advisory capacities can be instrumental to the success and quality of the effort. Advisory personnel can:

- Generate new research topics, or new hypothesis to be tested.
- Review and refine project goals and methodology. As the minutes indicate, our committee placed a high priority on including self-advocates on the workshop program.
- Share information from their own research activities. Some members of our committee were engaged in studies on consumer involvement, others had worked with self-help groups, and still others were leaders in the self-advocacy movement.

Our committee meeting generated some key research questions: What kinds of projects do self-advocacy groups sponsor? Do these activities really have anything to do with the programmatic mandates of VR agencies? If so, in what ways? How can the workshops help give VR officials an insight into what it's like to be part of the self-advocacy movement?

Following the meeting we began reviewing the literature and contacting self-help groups across the country. Three topics predominated throughout our research. The first concerned implementation of Chapter 25 of the Rehabilitation Services Manual. Chapter 25 requires state VR agencies to develop plans showing how clients, providers, and other concerned individuals would be involved in policy consultation. How much impact were self-advocacy groups having on agency policies? Did these plans settle all the issues stemming from the relationship between self-advocates and the agencies?

The second concerend the Client Assistance Projects (CAP's). What did these Projects tell us about the ombudsman concept? How did agency personnel react to CAP mediation between clients and counselors? Although the material we ultimately developed for the workshops did not include an extensive analysis of the CAP's, our views on consumer involvement were reinforced by the success of these Projects.

The third, of course, concerned the independent living movement. The IL movement stresses the need to fill the gap between what disabled citizens require to function within the community and what they receive from the service delivery system. Part of the uniqueness of this movement is that it merges political self-advocacy, i.e., articulating grievances, with self-help, i.e., redressing them.

THE LOGISTICS OF WORKSHOP PLANNING

ACCD's plan to conduct short-term training involved designing a module on "The Role of Self-Help Groups in Rehabilitation," and presenting that module during workshops for state agency VR directors or their designees. We conducted three of these workshops; one for VR agencies in the East, one for the Midwest, and one for the West.

Choosing a date, selecting a hotel --- or, in our case, three hotels --- and sending out pre-conference mailings are closely interrelated tasks. Our choice of hotels was restricted because not all establishments are accessible. The dates we originally selected had to be revised because we were unable to reserve the number of rooms we would require in those hotels available to us. After we did book the three sites, we had to delay our pre-conference mailings --- approximately five weeks past our intended date --- because two of the hotels failed to send us the reservation reply cards which had to be enclosed with each invitation.

These workshops were ACCD's first venture into the field of short-term training. Our staff was anxious to do its best and would have greeted any stumbling block with a degree of apprehension. It seems clear, however, that we did not allow ourselves sufficient lead time for logistics.

DESIGN: INTEGRATING DATA AND FORMAT

As our data mounted, we began giving increasing thought to format. How should the material be presented? Who should present it? What sort of format would serve both those VR participants who had a great deal of experience with consumer involvement and those who would be coming precisely because they did not? What evaluation methods should we use?

Lectures: Our research showed that though there were many questions surrounding the implications of self-advocacy, there were few comprehensive discussions on the matter. Materials on independent living, for example, were quite dispersed. The findings from the Client Assistance Projects had just been issued when we began our investigation and had yet to be analyzed in terms of the self-advocacy movement. Furthermore, many consumers and professionals alike seemed unclear about the requirements of Chapter 25. We had to ensure that these topics were covered during the workshop. There were too many questions on self-advocacy and Chapter 25 for us to rely exclusively on guest speakers.

The information we gathered formed the basis for the four lectures to be given at the workshops. We constructed our pre-test/post-test questionnaire concurrent with the development of the lectures. Following the first workshop, we shortened the lecture time slightly in order to bring a tighter focus to key concepts and to allow more opportunity for questions and answers. In addition, we designed special one-page Issue Guides that corresponded to the materials covered in each lecture.

The lectures were not scripted in the traditional sense. Each workwhop was unique and spontaneous. What remained constant throughout the project was the structure of the material; that is, our sense of and agreement on the issues that had to be addressed. ACCD will be expanding the material used in the lectures and publishing a book on self-advocate involvement in rehabilitation. The Issue Guides, however, form an excellent outline for those wishing to sponsor follow-up training workshops, and we are therefore including them in the section entitled "Training Module" which appears in this Manual. The "Training Module" brings together a full set of revised material developed for our short-term training project.

Consumer Involvement at the Workshops: Disabled citizens took a key role in the workshops, and served as presenters, facilitators, and active observers. Each workshop featured two types of consumer presentations; one in which a self-advocacy leader described a specific peer support program, and one in which a number of members from a self-advocacy group participated. In our first workshop, members from Disabled In Action of Pennsylvania held an actual DIA meeting. VR trainees were able to see for themselves who attends such groups, what topics are discussed, and how the volunteer committee structure compensates for the lack of paid staffers. In our second, members from the United Handicapped Federation in Minnesota presented a panel discussion on their initiatives in such fields as transportation, VR policies, and the concerns of sheltered workshop employees. In our third, a group from Berkeley's Center for Independent Living reviewed their work in peer counseling and legal advocacy.

Small Group Session: We did not want the workshops to consist entirely of lectures and presentations. Rather, we wanted to offer sufficient opportunities for trainee participation. Therefore, we interspersed the lectures with small group sessions. Two of the sessions featured a role playing exercise, while the third asked participants to draw up plans indicating how they were going to utilize concepts covered at the workshops when they returned to their state agencies.

The narratives developed for the small group sessions appear in this Manual. Role playing can be a risk. We've been told that sometimes the role reversal is unsuccessful, and that participants become "too polite." One of the things we noticed during our workshops was that, since the trainees had an insider's view of the rules of bureaucracy, they portrayed unusually adept disabled self-advocates in the role reversal sessions. We later found ourselves cautioning the trainees that not all citizens had as much inside information as they did. Despite these reservations, role playing can be a vital tool for soliciting trainee involvement. Many of our VR trainees told us that the exercise gave them a challenging and needed opportunity to see the world from a client's vantage point. It is, indeed, difficult to conceive of the workshops as not having had these sessions.

Guide to Self-Help Groups and Advocacy Organizations: Our advisory committee stressed the importance of showing the diversity of self-help groups throughout the country. They also felt that VR trainees should be encouraged to contact such groups. We therefore decided to assemble lists of all the peer-run groups known to us and distribute statewide directories. Though each state directory included some organizations that are operated by non-disabled (or, surrogate) advocates, its primary intent was to draw attention to self-advocacy organizations.

Most self-advocacy groups are small and have neither paid staffs nor office space. Often they use the home of their president as a mailing address; and a change in officers, therefore, sometimes creates problems in continuity. To facilitate relationships between such groups and VR agencies, our staff designed a special Organizational Outreach Form. The Form allows professionals to log dates of contact and record changes in group leadership. That form, along with an accompanying narrative, was included in each of the directories, and appears in this Manual as well.

The directory featured a series of descriptions of self-help projects sponsored by groups around the country. These "Profiles in Action" covered peer counseling, employments strategies, campaigns to remove architectural barriers, and more. They, too, appear in the Manual. ACCD is currently revising the lists it used in the directories, and will be publishing a nationwide Guide to Self-Help Groups and Advocacy Organizations.

Agenda and Staff Schedule: The first item in the section marked "Training Module" is a replica of our agenda for ACCD's St. Paul workshop. Following the agenda, however, you'll find a document which differs markedly from it in style and tone. This document, the STAFF SCHEDULE, is both less formal and far more detailed, giving you a behind the scenes look at exactly who was in charge of what, and, in some cases, of who would be responsible for arranging substitute programming. In our previous discussion on the fundamentals of planning, we discussed the importance of matching tasks to people, and deadlines to tasks. Agendas, in a sense, are illustrative of time and task planning, though we rarely think of them in those terms. Our STAFF SCHEDULE went that one step further which is characteristic of more precise planning strategies. Ideally, an entire project is broken down into detailed and manageable objectives. Though ACCD does not always chart its day-to-day activities with as much rigor as this document does, the STAFF SCHEDULE proved an invaluable guide during the workshops, particularly when unexpected events necessitated changes.

TESTING, SURVEYS, AND FOLLOW-UP EVALUATIONS

Because of the amount of research currently being sponsored by the government and private foundations, there is a growing emphasis on evaluation. When you apply for a grant reviewers will want to know how you plan to measure your results. Not suprisingly, there is a growing body of literature devoted to evaluation theory and testing procedures. In this volume, we cannot review the varied and complex issues associated with testing techniques. We can, however, tell you what we did and how we did it.

There are numerous methods of evaluating short-term training. In our project we used three:

The first, a pre-test and post-test, sought to measure the amount of learning that took place during the workshop. This method is basically an information-based approach. As we developed the lecture material we identified those concepts which we considered most important. We then designed a multiple-choice questionnaire to test the trainees' knowledge in those areas. The questionnaire was administered at the start of the workshop, and then again at its conclusion. Testing methodologies have strict rules. For example, in order for the process to be reliable the same persons who take the pre-test must take the post-test. You'll find, unfortunately, that towards the end of a workshop a number of participants generally leave early either because of back-home scheduling demands or because they must make certain flight connections. To safeguard the validity of the evaluation, respondents must identify their tests; either by including their names on the questionnaire or, if workshop planners feel that anonymity is important, by including their license or social security numbers. In that way staffers can be sure that only paired pre-tests and post-tests are scored.

Following the first workshop we make an item analysis of the responses to see which questions were answered incorrectly most often. As a result of this analysis we revised the questionnaire slightly and we strengthened the material in the lectures to focus more closely on key concepts. The revised questionnaire, the other evaluation instruments described below, and a discussion of how each was scored and interpreted appear in this Manual.

The second evaluation method we used was to test the relevance of the workshop to the trainees. This method may be considered decision-based testing, since it probes how useful the material is to the trainees' professional tasks. We asked participants to rate each component of the workshop --- lectures, presentations, small group sessions, etc. --- as either "very helpful," "generally helpful," "not particularly helpful," or "not at all helpful." The Manual includes a bar graph showing our cumulative results from the three workshops.

Since we were working with a large number of respondents, a testing scale of 1-4 was sufficient. However, if you are dealing with fewer participants --- say, less than fifteen people, you may decide you want a scale that allows you greater refinement. Such a scale might read as follows:

Very helpful	Generally helpful	Not particularly helpful	Not at all helpful
12 11 10	9 8 7	6 5 4	3 2 1

We have been using a third method in connection with our post-workshop evaluation. A follow-up questionnaire was mailed to VR participants several weeks after the meetings. They were asked to judge the usefulness of the training in terms of day-to-day agency activities before and after the workshops. This method may be considered behaviorally-based testing because it seeks to measure changes in procedures. Though the follow-up questionnaire appears in this Manual, our analysis of the results have not been completed as of this writing. They will be available by the end of the year.

The three methods we've just discussed, then, constituted our evaluation strategy for our short-term training project on the role of self-help groups in rehabilitation. However, in addition to the instruments we described above we administered a policy questionnaire during the workshops in order to gain a clearer perception of the level and effectiveness of self-advocate involvement within VR agencies. That questionnaire, and the raw data culled from it, appears in this Manual. (An analysis of this data was sent to you with your pre-Conference material).

YOUR TURN

We have attempted to take you step-by-step from the project's inception to its implementation and follow-up. And now we find ourselves at the beginning, still seeing a need for closer self-advocate and provider alliances, yet far more assured about the ability to fulfill it. Now it is your turn. Now it is our turn. Now it is time for coalition building.

SECTION II

This section includes the minutes of a meeting of the ACCD Advisory Committee on Short Term Training.

Room 817, 1346 Connecticut Avenue, N.W. • (202) 785-4265
Washington, D.C. 20036

American Coalition of Citizens with Disabilities Inc.

MEMO TO: Members and Observers,
ACCD Advisory Committee on Short-Term Training

FROM : Rita A. Varela, Special Projects

DATE : February 13, 1978

RE : 31 January 1978 Meeting

As promised, we are forwarding minutes of the Advisory Committee session. The meeting proved to be an unusually rewarding one. Your suggestions are now being incorporated into a revised program. I will keep you posted as we develop materials and procedures; and will be soliciting your continued input and feedback.

The Advisory Committee consists of:

- E. Russell Baxter, Commissioner, Rehabilitation Services State of Arkansas
- Frederick A. Fay, Ph.D., Director of Research and Training, Tufts New England Medical Center RT-7
- Ann Ford, National Paraplegia Foundation, Chicago, Illinois
- Judy Heumann, Deputy Director, Center for Independent Living, Berkeley, California
- Craig Mills, Florida
- Terrence O'Rourke, Associate Executive Secretary, National Association of the Deaf, Silver Spring, Maryland
- Joseph H. Owens, Executive Director, Council of State Administrators of Vocational Rehabilitation, Washington, D. C.
- Lawrence Pittinger, Department of Mental Health, State of Connecticut
- Reese Robrahn, American Council of the Blind, Washington, DC
- Phyllis Rebenfeld, Hunter College, New York, New York

Mr. Harold Shay, Director, Division of Manpower Development, RSA, and Dolores Watkins, Vocational Rehabilitation Program Specialist, RSA, attended the 31 January meeting as ex-officio observers. Mr. Baxter was unable to attend due to illness. Ms. Heumann was represented by Mr. Robert Funk, an attorney with CIL. Mr. Owens was represented by Ms. Mary Duncan of CSAVR. Mr. O'Rourke was unable to be present because of a schedule conflict. Dr. Fay was accompanied by Ms. Janet A. Minch of RT-7. ACCD Director Frank Bowe and Special Projects Manager Rita Varela represented the Project Staff. Mr. Michael Hartman and Ms. Marcia Miller served as interpreters.

The meeting began promptly at 9:30 A.M. in room 601, 1346 Connecticut Avenue, N. W., Washington 20036. As with all facilities used by ACCD, the meeting quarters were fully accessible.

Hal Shay and Frank Bowe offered background briefings on the events which led ACCD to seek a grant to provide short-term training for the Rehabilitation Services Administration. The training would take the form of three workshops which will seek to offer rehabilitation professionals a better understanding of the role of self-help organizations in the VR process. (By self-help organizations we mean groups that are run for and by disabled citizens, and that either provide services -- such as the Center for Independent Living -- or serve as advocates -- such as Disabled In Action of Pennsylvania.)

Hal Shay noted that studying consumer involvement is one of the current priorities in rehabilitation research and training: RSA officials and State agency personnel want to know how to identify successful self-help groups in different areas, how to utilize the resources of these groups, and how to help consumers understand the mission and restraints of state VR programs. He added that the ACCD project is one of the early steps in what is envisioned as a continuing training process in the field of consumer involvement.

The participants at the Advisory Committee meeting were as concerned with the philosophy of the proposed workshops as they were with specific training details and presentations. This interweaving of concerns mirrored the fact that the whole concept of VR partnerships with self-help groups is relatively new and certainly multifaceted in nature. The participants stressed the fact that consumer involvement would gain greater acceptance once professionals became more familiar with what self-help groups could accomplish.

Robert Funk reviewed some of the programs sponsored by the Center for Independent Living. These programs, he said, illustrate both the benefits and the risks which may await the state VR system as result of expanded consumer involvement. CIL, for example, teaches disabled persons about their rights in designing individual rehabilitation plans. Thus, some VR clients have become more assertive. CIL also offers peer counseling and housing referral servcies, which help consumers become less dependent on public agencies. Though some professionals view CIL as bieng in an adversarial role and react defensively to its efforts, Bob noted that others are working quite closely with the Center.

Reese Robrahn commented that many cities do not have strong self-help or self-advocacy organizations; and that in order to insure the development of such groups, consumers and concerned professionals must work together to implement Chapter 25 of the Rehabilitation Services Manual.

Workshop Focus: How Much Impact? Who Should be Trained?

Larry Pittinger raised the issue of the impact of the workshops. Would the skills and the awareness gained during the workshops ripple through the system? How would the trainees deal with resistance from those colleagues who had not attended the workshops?

This discussion -- of whom we should seek to train in order to maximize the impact of the workshops -- took up much of the morning's session. Craig Mills posed the question in another way: Should we be training trainers, who would return home and transmit their skills to other professionals? Or, rather, should we be training individuals who will serve as catalysts: who will return home, begin working directly with self-help groups, and expand consumer involvement by the examples they set and the successes they have?

Since the States already have funds available for manpower development and training, Hal Shay tended to oppose the concept of training trainers. However, he mentioned that there were plans to sponsor a National Workshop on Training and that the ACCD might start thinking of ways to present its findings from this workshop project to the national forum.

The question of whom we should train (and of how many trainees we should have) proved a difficult one, and the discussion became increasingly specific. Some participants seemed uncomfortable with the fact that only sixty individuals would be trained. They asked who would be invited and how those decisions would be made. Do we want one trainee from each State? Three from twenty States? Six from ten States?

Mimi Duncan emphasized the fact that CSAVR's support of consumer involvement as a priority has been the result of a process of emerging consensus. She noted that many States have a general VR agency and an agency of services for blind people. CSAVR, therefore, has eighty-four members; and if we limit the number of trainees to sixty, some State Administrators would be unable to send representatives. It was suggested that ACCD might want to ask the RSA for additional funding to increase the number of participants invited.

The discussion returned to the issue of impact. What kind of trainees would best serve our objectives? Slowly, the group began focussing upon the concept of aiming the training at State VR decision-makers -- and those individuals who set policy and who can insure that it is carried out. Fred Fay said that the workshops should be aimed at the State VR director or the director's designate. The group also felt that, since some directors probably would send designates, our letters announcing the workshops should state very clearly what kind of training we would be offering and what we hoped the training would achieve in terms of "back-home" application.

There was, therefore, clear agreement on two precepts: First, that the training seek to influence top-level decision-makers; and second, that in announcing these workshops we take great care to explain who was being invited, what kinds of trainees we hoped to see at the workshops, and why the total number of trainees was restricted.

VR Attitudes and the Role of Disabled Individuals at the Workshops

The Committee observed that one of the chief barriers to better cooperation between VR and consumers is that neither side fully shares, nor understands, the feelings of the other. Fred fay suggested that before trainees can begin to open up to the new skills and awareness which the workshops offer they may need to ventilate their feelings; perhaps through a mock hearing or some other sensetizing experience.

Many participants stressed the importance of having disabled individuals serve as presenters and resource persons during the workwhops. Craig Mills emphasized that the workshops should provide very specific examples of how self-help groups can have an impact on the service delivery system. The group also talked about peer counseling, consumer-taught independent living skills, and the CIL's job advocacy programs. Craig Mills advised the workshop designers to think of all the objections which VR might make to self-help groups that seek assistance (such as the notion that the agency can't provide block grants, only individualized funds), and then try to present answers. He urged that we distribute information on innovation and expansion grants.

In remarking on the reluctance of VR professionals to extend funds, Janet Minch noted that a self-help group can enhance its position if it can show that it can fulfill its contractural obligations. If a group wants a grant to sponsor a transitional housing assistance program, for example, it must be able to demonstrate that it has a detailed plan, that it has or can recruit the necessary personnel, and that it has some knowledge in this area. Larry Pittinger agreed: he noted that State people have limited funds, and that before they commit them they want to know whether they'll get their money's worth.

There was, thus, wide agreement that consumers -- drawn from different disability groups -- should play a prominent role as resource persons, staffers, and presenters.

The Committee stressed that the legislative implications of expanded VR and consumer cooperation must not be ignored, but, rather, should be highlighted. The participants felt that VR needed a more active constituency, and that disabled individuals, as an outside source of support for agency legislative requests, could be tremendously effective in that role.

Larry Pittinger summarized the discussion on attitudes and cooperation by noting that in order to make consumer involvement work both sides have to know what they're getting. Consumers must have a sense of empowerment -- must feel that they aren't simply being co-opted, but rather are being heard and heeded. State VR people have to feel that self-help groups are providing usable advice and cost-effective services.

Organizing the Workshops: Faculty, Evaluation, and Follow-up

Since the participants had agreed that we should use local consumers as presenters to highlight successful examples of self-help efforts, Fred Fay suggested that we rely on a core faculty which would appear at each of the workshops and thus provide a certain degree of continuity in the training curriculum.

Selected State directors could also serve as presenters, and discuss how decision-makers can facilitate an environment which enhances VR and consumer cooperation. Craig Mills observed that often State directors will respond to innovative ideas: that if another State director has introduced a successful consumer involvement program, or if a trusted staff person within the department strongly believes in a certain project, the Administrator will be motivated to act.

Both Craig Mills and Reese Robrahn urged that the project develop a check list which would not only include the different types of consumer involvement activities cited in Chapter 25 but also give a number of examples of each. For each listing there would be a brief description of the project plus a name and address to which trainees could write for further information. The check list would also serve as a self-test, giving trainees a spectrum of options by which to compare their State plans.

Participants offered a number of suggestions concerning documents we should distribute at the workshops. Bob Funk mentioned a paper written by Ed Roberts, the California VR director, which discussed the concept of independent living. ACCD's forthcoming study on cross-disability cooperation was also discussed. Participants urged ACCD to seek additional funding in order to insure that the material developed for the workshops could be made available to other professionals.

The Committee then turned to the topic of methods for evaluating the project. Participants reviewed three types of measurements: A) Attitudes -- how did the trainees feel towards self-advocacy groups before and after the workshop sessions? B) Information -- how much did trainees know about self-help groups, about how to locate them, how to establish constructive relationships with them, and how to help them become more effective, before and after the workshop sessions? C) Behavior -- what kinds of contacts, if any, did the trainees have with self-help groups before and after the workshop? In addition to pre-and post-tests, the Committee recommended that the staff develop follow-up evaluation instruments to determine if trainees implemented any of the skills they acquired at the workshops. Fred Fay noted that RT-7 had several instruments which could be adapted for use in the project. It was also suggested that ACCD notify its member groups about the workshops so that local consumers could contact trainees.

Conclusions

(1) Trainees are to be State VR Directors or their designees. Future training workshops would follow up in greater depth with "front line" personnel.

(2) The training should feature considerable consumer-professional interaction, both formal and informal. The first day's session should begin a bit later than originally planned and we should schedule an informal get-together during the evening preceding the first day's sessions to allow trainees and project staff to interact in a casual, unstructured atmosphere.

(3) Invitations should be extended to all 84 State VR agencies. ACCD should seek whatever supplemental funding might be necessary to accomplish this objective.

(4) The workshop should provide highly specific and detailed information, including resource guides, the Chapter 25 check list, and related materials.

(5) The aim of these three workshops is to stimulate VR Directors to accelerate the agency's consumer involvement efforts, as well as to solicit additional training for staff members designated by the Directors.

If I have omitted anything you feel is important -- or misstated any comments made -- please notify me immediately.

I will be in touch shortly on how we will implement your recommendations.

Thank you, again, for your cooperation and advice.

SECTION III

This section includes the Training Module developed for our workshops on "The Role of Self-Help Groups in Rehabilitation":

- Agenda
- STAFF SCHEDULE
- Issue Guide I
  Small Group Session One: State Director's Meeting
  (Role Playing)
- Issue Guide II
- Small Group Session Two: Coalition Meeting
  (Role Playing)
- Issue Guide III
- Small Group Session Three: Formulating a Plan
- Issue Guide IV

ACCD CONFERENCE ON SELF-HELP GROUPS IN REHABILITATION

AGENDA

Day One

9:00 - 9:15 a.m.	Coffee, Registration
9:15 - 9:30 a.m.	Welcome, Pre-Test
9:30 -10:00 a.m. =	INTRODUCTION purpose of conference review of format and content small-group assignments
10:00 -10:30 a.m.	SELF-HELP GROUPS: WHAT, WHY, WHERE
10:30 -10:45 a.m.	Coffee Break
10:45 -12:00 noon	SMALL GROUP SESSIONS
LUNCH	
1:15 - 2:00 p.m.	REPORTS FROM SMALL GROUPS
2:00 - 2:30 p.m.	Discussion, questions
2:30 - 3:00 p.m.	RESOURCES OF SELF-HELP GROUPS - AND HOW TO TAP THEM
3:00 - 3:30 p.m.	CONSUMER PRESENTATION
3:30 - 3:45 p.m.	Coffee Break
3:45 - 4:45 p.m.	SMALL GROUP SESSIONS
DINNER	
7:30 --	SELF-HELP GROUP PANEL You are cordially invited to a special panel discussion presented by the United Handicapped Federation of Minnesota

Agenda cont.

Day Two

8:45 - 9:00 a.m.	Coffee Break
9:00 - 9:15 a.m.	Special Policy Questionnaire
9:15 -10:45 a.m.	SMALL GROUP SESSION
10:45 -11:00 a.m.	Coffee Break
11:00 -11:30 a.m.	ENHANCING THE CAPABILITIES OF SELF-HELF GROUPS
11:30 -12:00 noon	Discussion, Questions, POST-TEST
LUNCH	
1:15 - 2:00 p.m.	REPORTS FROM THE SMALL GROUPS
2:00 - 2:45 p.m.	BRINGING IT ALL TOGETHER: TRANSLATING POTENTIAL INTO ACTION
2:45 - 3:00 p.m.	Evaluation Sheets
3:00 --	ADJOURNMENT

Notes to the STAFF SCHEDULE:

The STAFF SCHEDULE, as we noted earlier, was highly informal in tone and yet very specific. We decided to duplicate it for you as is, without any cosmetic changes. However, a few explanatory notes may be in order.

- Rose Ann - Mrs. Rose Ann Jackson, Secretary, ACCD staff
- Owens - Mr. Joseph H. Owens, Executive Director, Council of State Administrators of Vocational Rehabilitation (CSAVR)
- Duncan - Ms. Mary C. Duncan, Administrative Assistant, CSAVR
- Rita - Rita A. Varela, Special Projects Manager, ACCD
- Toby - Mr. Charles (Toby) McCoy, Administrative Assistant, ACCD
- Frank - Dr. Frank G. Bowe, Director, ACCD
- Ellen Daly - Executive Director, Greater Milwaukee Area Chapter of the National Paraplegia Foundation
- UHF - United Handicapped Federation of Minnesota

STAFF SCHEDULE

IN OFFICE

Friday

MATERIALS:

a) Directories (#_____Extras #_____)

b) Packets (#_____Extras #_____)

c) Tests: materials for facilitator (#_____)

d) Name tags - Type list for Rose Ann (include staff, Owens, Duncan...)

e) Are the Policy Questionnaires ready?

The person who will carry materials to Airport.

Monday

Check arrangements with hotel (Rita, Toby)

a) Change coffee hour on Tuesday from 9:00 a.m. to 8:45 a.m.

b) Write down names of three conference rooms

c) Place packets at hotel registration desk
DO WE HAVE NOTES FOR EACH GUEST (OR A LIST, XEROXED?)

SPEAK WITH FACILITATORS (RITA,TOBY IF AVAILABLE)

a) Hand out facilitator material; read aloud, discuss approach

b) If UHF cannot attend, there may be a panel discussion on Monday evening with the following people.

A__________ B__________ C__________ D__________

STAFF SCHEDULE - page 2

(Day One)

8:45 a.m. Bring uncollected materials from front desk to registration desk (TOBY)

9:00 - 9:15 a.m. Workshop Registration; coffee

- a) Need list of participants
- b) Registration desk will be manned by Toby

9:15 a.m. Introductory Remarks and Announcements (FRANK)

- a) Announcing rooms for small groups, etc.

PRE-TEST

- a) Pre-test will be handed out & collected by TOBY
- b) In case some trainees need readers they will be assisted by TOBY

9:30 p.m.(approx) (LECTURE I) SELF-HELP GROUPS: WHAT, WHY, HOW (Frank)

- a) Lecture will include a slide presentation

  Hotel will provide screen for slides

  Slide projector & slides will be brought

  and operated by TOBY

10:30 - 10:45 a.m. COFFEE BREAK

10:45 - 12:00 Small groups sessions (Penmar State Director's Meeting)

12:00 - 1:00 LUNCH - ON YOUR OWN

1:15 - 2:00 p.m. Reports from the small groups

The person standing at the podium to call on (recognize) the small groups (Rita)

2:00 - 2:30 p.m. Discussions, questions

The person at the podium during discussions RITA

2:30 - 3:00 p.m. (LECTURE II) Resources of Self-Helf Groups
How to Tap Them
(FRANK)

3:00 - 3:30 p.m.	Consumer Presentation - Ellen Daly
3:30 - 3:45 p.m.	COFFEE BREAK
3:45 - 4:45 p.m.	Small Group Session (Penmar Coalition meeting)
5:00 - 7:15 p.m.	DINNER - ON YOUR OWN
7:30 - 8:30 p.m.	UHF Panel If UHF cannot attend, there may be a panel discussion with the following people: A__________ B__________ C__________ D__________ The person who will check (Rita)
8:30 - ???	CASH BAR

(Day Two)

8:45 - 9:00 a.m.	Coffee
9:00 - 9:15 a.m.	Questionnaire (TOBY OR RITA) The staff person in charge will be (TOBY OR RITA)
9:15 - 10:45 a.m.	Small group session
10:45 - 11:00 a.m.	COFFEE BREAK
11:00 - 11:30 a.m.	(LECTURE III) Enhancing the Capabilities of Self-Help Groups (JOE OWENS)
11:30 - 12:00 noon	Questions, Discussion, POST TEST
12:00 - 1:00 p.m.	LUNCH - ON YOUR OWN
1:15 - 2:00 p.m.	Final reports from the small groups. (RITA at podium)
2:00 - 2:45 p.m.	(LECUTURE IV) Bringing it all together: Translating Potential into Action (RITA)
2:30 - 3:00 p.m.	Discussion, Questions
3:15 p.m.	ADJOURNMENT

ISSUE GUIDE I

SELF-HELP GROUPS: WHAT, WHY, WHERE

- In recent years we've seen the emergence of self-help and self-advocacy groups. These groups, founded and operated by disabled individuals, have grown in size and influence. Some groups are concerned mainly with speaking out on public issues, others provide services such as peer counseling or housing referral, and still others do both.

- At times the relationship between providers and self-advocates has been adversarial. Yet, we also find that when both groups begin talking together attitudes change and barriers give way to sharing.

- The disability rights movement influenced the debate and design of the Rehabilitation Act of 1973. Congress heard the voices within the movement and called for expanded participation of disabled citizens in rehabilitation planning. Chapter 25 of the Rehabilitation Services Manual, which was issued in 1975, requires states to develop a plan which will include recipients, former recipients, advocates, providers and concerned citizens in the process of policy consultation.

- Not all of the disabled individuals who belong to self-help groups are VR clients: some are, some are homebound, and some have full time careers.

- These tend to be multi-issue groups, with some members concerned with VR service delivery, some with transportation, some with independent living, and some with public awareness.

- Self-help group meetings tend to be small, attracting ten to twenty people. Transportation problems make it difficult to get disabled people together. The group, however, may have a mailing list of several hundred persons.

- The members know that different officials have authority over different matters. Self-advocates often seek to build relationships with both administrators and politicians.

- There is a lot of paper work involved in keeping an organization going. These groups tend to be volunteer operations, few have an office or staff. Most of the work tends to be done by a handful of loyalists.

- Being in a group presents the same problems of interpersonal communications, decision-making, conflict, and conciliation to disabled persons as it does to non-disabled persons.

STATE DIRECTOR'S MEETING: SESSION ONE

Your group is a coalition of consumers and advocates in the state of Penmar, a medium-sized East-coast state of moderate political tenor. The group was recently incorporated. Its formation is due largely to the efforts of one dynamic individual who has convinced one dozen consumer leaders to at least call a moratorium on in-fighting to give "unity" a chance. The 12 leaders represent a total of 20 organizations of and for disabled people (eight represent two groups each). These 20 organizations are among the largest in the state, but still number only 250 unduplicated individuals among their members. Remaining outside the coalition, watching "how it works" or opposing its creation are about 35 organizations of and for disabled people, which have about 500 unduplicated members in their rolls. The 35 "outside" groups are a motley lot: most are social and recreational in nature, but three are very active politically and are led by charismatic figures who are apparently unalterably opposed to cross-disability coalition.

The coalition's annual budget is $575.23. It has raised this sum through a mail campaign financed by a friend of the dynamic man who instigated the coalition. The letters, which he signed, promised a "vigorous and unified effort to bring Penmar DVR into the 20th Century." The issue appears to be one of broad interest and wide support. The 20 organizations represented by the 12 leaders all agree that VR must be made more responsive to actual needs of disabled Penmarers. Differences remain, however, about how to do this. Some favor direct mail, phone, and in-person visits to the state legislature demanding change. Others think demonstrations would be more effective. A minority favors writing to the RSA Commissioner in Washington demanding an investigation. Through a two-hour debate, a compromise was reached: the group will first meet with the state agency director. If he is not responsive, the group will re-convene to consider its next steps. The second motion passed was to create an ad hoc task force charged with determining specifically "what is wrong" with Penmar DVR. The task force's report is appended.

The group's Corresponding Secretary reports that a letter accepting the coalition's request for a meeting with the state agency director has been received.

State Director's Meeting, 2

The debate on how to approach the Director and what to say is heated. Among the points to emerge are:

(1) The director might try to "divide and conquer" us by playing one disability against the other.

(2) The outsiders are watching very closely. If we don't do this right, the whole coalition might collapse.

(3) How can we convince the state director that we "represent" the agency's constituency?

(4) We need to make specific, not general, points.

(5) Some of us favor a "get-tough" approach to show the director we can't be pushed around; others favor a politic, "professional" demeanor. One woman says: "I'm not even sure we're together on this."

(6) Should we tell the state director what we might do if we're not satisfied with his response, or should we keep our options open?

(7) The President reviews the group's top priorities (set in a previous meeting):

   a. interpreters for the deaf and readers for the blind shall be provided in all education, rehabilitation, and social service settings at no charge.
   b. architectural and transportation barriers must be removed as required by section 504.
   c. the number of VR clients must be increased.
   d. the quality of services for severely disabled clients must be improved.
   e. the VR agency must use its influence to make other social service agencies more responsive to disabled people.
   f. the state civil rights code must be upgraded.

YOUR PROBLEM: Devise a strategy for a meeting with the state director that will maximize your chances of reaching the coalition's goals, keeping the group together, "neutralizing" or recruiting the "outsiders," and responding to any evasive or non-productive replies by the state director.

You have 45 minutes. At 11:30, a workshop leader will come to your group to play the role of the state director.

TASK FORCE REPORT ON PENMAR DVR

The Penmar DVR is, compared with other state DVRs, of about medium size. The Director is appointed by a State Board of Education. He is a Republican with moderate views on social action and relatively conservative views on fiscal policy. One of his problems is that the State Board is so concerned with declining school enrollments and the attendant problems---what to do about highly unionized teachers resistant to layoff or transfer, how to dispose profitably of no longer needed property, etc.---that it pays relatively little attention to rehabilitation.

Over the past four years, the number of severely disabled clients accepted into the program has increased to the point that such clients now number 41% of the number of clients admitted. However, there is a very rapid drop-off among these clients. A sizeable minority are terminated in non-26 closures. Services to these people have not noticeably increased over the past four years.

In his public statements, the Director has said that "the failure of the Congress to markedly increase appropriations for such a cost-effective program as VR has meant that we have not been able to do our job as effectively as we might wish. I would be the last to advocate fiscal irresponsibility. However, for a program that returns as much as seven dollars to the public treasury for every dollar expended, the support from the Congress has been disappointing." The Director tends to blame lack of money, State Board inattention, and the Congress for all of his problems.

Rehabilitations (closed as "26" or homemaker closures) have declined since 1973. Factors which might be at cause but which the Director has not publicly acknowledged include: counselor training (few have an M.A.), morale (absenteeism is higher each year), lack of basic supportive services (because of fiscal limitations, it is alleged) which mean that deaf and blind persons often do not have full access to communication, and bureaucratic inefficiency.

The Director has not set VR in a leadership role with respect to section 504. While he says the agency will comply, he does not see VR as the appropriate agency to influence compliance by other state agencies. Nor has he shown much interest in our goal for civil-rights law reform in Penmar.

STATE DIRECTOR'S MEETING: GROUP LEADER GUIDE

FOR PLAYING THE ROLE OF THE DIRECTOR

1. Tell the group how pleased you are that they are interested in Penmar DVR. Say how proud you are of the agency's efforts on behalf of disabled Penmarers. "With very limited funds and strict legislative restrictions on what we can do with that money, I think we're doing very well indeed." Tell the group that you look forward to a "cooperative" and "helpful" discussion. Then ask: "What's on your minds, folks?"

2. When they present a demand that you're not really willing to grant, say: "Well, that's interesting. But before I act, I want to be absolutely sure that this is what Penmarers who are clients and potential clients of our agency really want. How can I be sure that some group won't come in here tomorrow and denounce everything you've just said?"

3. If they ask for something for one group or a few groups (say: deaf, blind, etc.), say: "That's all well and good. But that will just make the other disability groups mad at me."

4. If you detect any difference between group members---one person who seems to "hear a different drummer"---single him out for praise: "Now, what I really like is an original, courageous thinker like yourself. Not to disparage the rest of you, but I think we need more open-minded disabled like you."

5. Near the end of the meeting, say: "Well, you know I want to help. That's what I'm here for. But I want to be sure that I'm helping my constituency---clients and potential clients. And I want to be sure that if I help you, you'll go to bat for us when it's to both our advantages. Are you prepared to do something for all Penmarers who are disabled? Something like getting the State Board of Education more involved in VR? What can you do for me?"

6. If they threaten you---"We'll go to the Commissioner in RSA! We'll go to the Legislature!" etc., say: "O.K. Go ahead. Good luck."

7. At the end, say: "Thank you. It's been a good meeting."

ISSUE GUIDE II

TAPPING THE RESOURCES OF DISABLED INDIVIDUALS AND SELF-HELP ORGANIZATIONS

- Bureaucracies are highly complex systems of rules which specify the appropriate responses to many situations. Through bureaucracies we can keep numerous, multifaceted sets of situations operating in reasonably predictable order. Bureaucracies tell us what happens next.

- People who work within bureaucracies have a responsibility to ensure that tasks are performed in an orderly fashion. They are concerned with process, with how things are done. People outside of the system are concerned with the end results of the process, and with how long it will take. Sometimes disabled people fear that time will run out before the system gets around to their concerns.

- Professionals have often taken a management-oriented approach to VR, emphasizing case handling and, when necessary, purchasing services which the agency did not offer. Professionals have sought to concentrate on specific tasks and proven strategies. Many consumers have taken a broader view, urging agencies to adopt more aggressive approaches to independent living, affirmative action, and inadequate transportation.

- Though Chapter 25 lists a number of ways to involve persons in policy consultation, it does not mandate any particular structure or method. Many states have advisory councils. Some have ombudsmen programs and hotlines. Others give grants for programs which a run by self-help groups. Such programs include information and referral, peer counseling, job advocacy, and training for independent living.

- The prospect of increased consumer involvement and client assertiveness in rehabilitation has caused anxiety among some professionals. The results from the Client Assistance Projects, however, reveal that increased involvement brings better client-counselor relationships, greater client commitment to his/her particular rehabilitation plan, and new staff training techniques.

- Professionals can best learn about self-help groups through personal contacts. When possible, they should call instead of writing or sending notices, and should try to attend self-help group meetings.

COALITION MEETING: SECOND SESSION

You are the "top brass" of Penmar DVR: the agency director and his policy aides. After the meeting with the group (session one), you've been surprised by the coalition's effectiveness. It's grown a bit in size, begun to stabilize around a "middle ground" that both radicals and moderates can live with, and focussed upon a concrete set of objectives. While the group still has a long way to go--it's still by no means "representative" of all consumers let alone all clients in Penmar, its' budget is still quite small, it still has its little battles and gaffes--you're convinced it's "on the verge" of becoming an effective self-help group.

You want to know more about the group---who its leaders are, what groups belong, what the dynamics are that make it move (or could cripple it). You want to know more about what it could do that would not only advance its objectives but also help you meet Penmar DVR's goals.

One problem: the group gradually has shifted ground. Rather than focussing primarily upon DVR policy, the coalition has been trying to get state agencies and community service programs to comply with section 504. While you think this is an important activity, you hope that you can tap the group a bit more so that DVR ends may also be served.

You hope to set up a truly effective consumer involvement process within the agency. Looking over Chapter 25 and your options for consumer input in policy-making, research, training, facilities, and other areas, you want to identify some means that will go beyond just compliance with Chapter 25 and really advance the agency's work.

And the fact that the coalition is not yet truly representative bothers you. You are tired of receiving conflicting advice and demands from groups that don't even talk to each other. You've come to see that coalescing into coalitions serves not only disabled people but public agencies as well.

YOUR PROBLEM: How will you start? What will you do?

You have 30 minutes. At about 4:15 a group leader will come to you to play the role of the coalition's president.

COALITION MEETING: SESSION TWO

Group Leader's Guide for Playing the Role of President of Penmar Coalition

1. Open the meeting by saying that you're pleased to be here but you're not quite sure why they invited you.

2. Express a little suspiction. "I don't understand. When we last met, you were very dubious about how "representative" we were. Now you're coming to us. How do I know you're not trying to buy us off?"

3. If they offer a grant or contract to do something, express some reservations: "We're not really set to do that kind of thing yet. I'm still trying to build up the organization so that it will be effective. We need some resources before we can really act. And besides, none of us understands how to write grant proposals."

4. At some point, say: "I want to be sure that if we do this or something like it, our goals as well as yours will be served. How can we accomplish that?"

5. End the meeting by saying: "I'd like to invite you or one or two of you to come to our next meeting. I want to introduce you to some of our people so you will better understand us---and so we can better understand you. Would you be willing to come to our meeting next Saturday night?"

6. End the meeting with a "Thank you."

ISSUE GUIDE III

ENHANCING THE CAPABILITIES OF SELF-HELP GROUPS

- Providers and self advocates have different vantage points and use different sets of jargon. Providers think in terms of quantifiable performance standards, caseloads, and cost-effectiveness. Disabled activists think in terms of barriers, advocacy, and self-determination. These differences may obscure common goals. A liaison, who helps expose each to the frame of reference of the other, can help both learn and grow.

- Not all disabled individuals will respond to an agency liaison in the same way. Some will welcome the prospect of closer cooperation with VR, some will be suspicious, and some will strongly oppose such ties. Some consumers may have had negative experiences with a counselor, and may not be totally objective.

- A good facilitator learns to work with people as they are, and in so doing helps them become more than they are.

- As consumers interact with the VR liaison, they will become more familiar with the agency's concern for evaluation criteria and principles of sound management. Self-help groups may have many questions --- and misconceptions --- about grants, decision-making within the agency, and resources. The liaison can provide guidance as self-advocates find their way through the bureaucracy. The liaison, because of his/her personal involvement with self-help groups, becomes an advocate and helps to ensure that the process does not stall, and that papers or requests do not wind up on the wrong desk.

- Disabled citizens can help agencies evaluate current programs and design pilot projects. In order for citizen advisors to serve as true spokesmen, however, they must be in touch with others in the disabled community. The question of whether consumer advisors are speaking for constituents or merely for themselves is an extremely delicate question which, unfortunately, has at times been asked abrasively by professionals. It is, however, a key issue in consumer involvement.

- The agency may want to know what contacts disabled advisors have within the disabled community, whether they belong to a consumer group, and whether they report back to its members. In addition, the agency may want to publish reports about its activities in consumer newsletters, in order to ensure that a large number of persons in the disabled community have equal access to important information.

- One way to approach the issue of the representativeness of advisory groups is to ask all major self-help groups in your state to elect one person who will serve as a consumer liaison to VR, and to have the groups themselves set guidelines specifying how that person will report back to the group. This approach may not be perfect, but it is one which the agency shares the responsibility of selecting advisors with the self-advocates themselves.

FORMULATING A PLAN: SESSION THREE

We've structured this workshop as a conference for state directors and their top policy aides. Frankly, we're hoping that you will be able to return to your states and stimulate some new activity in the area of consumer involvement through self-help groups.

We'd like you to use this time to formulate specific plans. What will you do when you return home? How can you set specific goals and objectives for your people? What will be some of the next steps you will take?

We've allocated 90 minutes for this small-group session. You might want to use the first 45 minutes for a general discussion, the next 30 minutes for individual writing, and the final 15 minutes for instructing the group representative on what to report to the conference participants in the afternoon session.

Some points you might want to consider:

(1) How satisfied are you with your consumer advisory body, if you have one? How might it be improved?

(2) What ways other than an advisory body might be available for consumer involvement in your agency? Which seem good to implement immediately upon your return home?

(3) What additional information will you need before you can really move on this? What sources might you tap for this information?

(4) Do you see a need for a follow-up workshop on self-help groups, this one geared for firing-line personnel in your agency? If so, what would you want such a workshop to teach your people?

A group leader will be available as a resource person during your discussions.

ISSUE GUIDE IV

POLICY IMPLICATIONS OF CONSUMER INVOLVEMENT

o Chapter 25 raises the issue of who do consumer advisors represent but does not offer guidelines to ensure representativeness. A representative can be seen as either someone who speaks for a group of people or someone who is reflective of a group of people.

If Congress is elected by the citizenry, then Congressmen are responsible to the voters and the voters are responsible for the quality of the Congress. If, however, a chief of state appoints a congress, we have a different situation.

In the case of consumer involvement, agencies are faced with a dilemma: Even if they wanted a truly representative advisory structure, they wouldn't be able to afford the electoral mechanisms which go with it.

o Meaningful involvement, therefore, requires more than a written plan that uses words like "representative" of "input in decision making." It requires, first, a recognition that there may always be problems in assuring representativeness, and, second, a commitment to outreach --- to making sure that consumers and self-help groups hear about the agency's efforts to listen to and work with them. An agency's policy consultation plan must be both written --- i.e., with specified rules, powers, and procedures --- and acted --- i.e., a people-to-people process in which individuals from the agency and from the disabled community schedule opportunities which allow them to influence each other.

o In a society in which professionals are under pressure to specialize, to look at increasingly smaller pieces of the puzzle with increasingly larger magnifying glasses, citizen participation can be a creative force in policy making.

The independent living movement has made us more aware of the need to address the gaps in our service delivery system, has shown us that accessible environment is a crucial factor in rehabilitation outcomes, and has taught us the value of peer counseling and peer support.

o Self-help organizations can, and have, conducted seminars and training on 504, legal advocacy, and accessible environment. Since consumer organizations tend to utilize a lot of volunteer expertise, their overhead tends to be far less than that of traditional consulting firms.

o Though Chapter 25 relates specifically to VR policy consultation, it reflects a response not just to those who are rehab clients but to the disability rights movement in general.. Not all disabled individuals join groups, write letters to Congressmen, testify at public hearings, or march in front of RSA. Not all non-disabled individuals become involved in civic issues either.

Those people who do become involved in issues constitute an "attentive public;" and are more aware of and active in matters relating to that given issue than is the general public.

The disability rights movement, which is made up of clients, homebound citizens, disabled students, and disabled citizens who have full time careers, are a very attentive public.

SECTION IV

EVALUATION: INSTRUMENTS AND RESULTS

This section includes all of the evaluation instruments used in connection with the workshops, plus our Policy Questionnaire.

It also includes the following samples from our tabulations:

- Pre-test/Post-test results - St. Paul
- Item analysis of errors - Pre-test/Post-test - St. Paul
- Bar graph showing cumulative results (i.e., from all three workshops) of Participant Evaluation Sheets
- Results of the Policy Questionnaire survey

Tabulating the Survey Instruments [1]

I. Pre-tests and Post-tests

A. Average score: Each pre-test was scored to determine the number of correct answers on that pre-test. The scores of the pre-tests were then added to obtain a total group score. This total was divided by the number of pre-tests scored to obtain the average pre-test score.

The same steps were taken to determine the average score on the post-test.

B. Item analysis of errors: A chart was designed as pictured below:

	a.	b.	c.	d.
1				X
2		X		
3			X	

Notice that the vertical row is made up of the numbers of the various questions on the test. The horizontal row is made up of the letters of the answers the respondant had to choose from. The square with the X mark designates the correct answer for the question number appearing to the left of the X.

We then went through the tests. When an incorrect answer had been given for a question, we placed a mark in the corresponding square to indicate on which question the error occureed and which erroneous answer had been given. The result of this tabulation is an "item analysis of errors".

To provide extra information, we tallied up the errors on each question to determine the total number of errors on that question and, then, added these numbers together to obtain the toal number of errors on the pre-tests (or post-test, whichever we were dealing with). By dividing this total by the number of questions on the test, we found the average error rate. Since we were concerned with improving the questions missed most frequently, we then listed which questions had been missed more than the average rate.

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[1] All the tabulations for the pre-tests/post-tests, the evaluation questionnaire, and the policy questionnaire were done by Mr. Charles McCoy, who served as a tireless and invaluable administrative assistant during the course of the workshops. Mr. McCoy authored this section on "Tabulating the Survey Instruments".

C. T-test for significant difference in the pre-test scores and the post-test scores: This is not a difficult process but it would be difficult to put into words. It is most important that one realizes that a t-test for related samples is the proper form of the t-test to use. (There is another t-test for independent samples, eg. the height of males as compared to the height of females. A pre-test, post-test design always requires the related samples test). Also, as we discovered, it is absolutely essential that one be able to match the pre-test of someone with his or her post-test... afterall, the two are related! The t-tests are basic tools in statistics and any elementary statistics text describes them fully. We used the following text:

> Roscoe, John T., Fundamental Research Statistics for the Behavioral Sciences, (New York: Holt, Rinehart and Winston, 1969), pp. 170-171.

II. Evaluation

On the evaluation sheet, the participants were asked to rate the helpfulness of the various components associated with the workshops. We decided to construct a bar graph showing the results. The questions on the evaluation sheets designated "most helpful" as option number 1, "generally helpful" as option number 2, and so on. On the bar graph, however, we reversed the numbering of the designations---i.e., "very helpful" was designated as number 4, "generally helpful" was number 3, etc. The actual tabulation of the evaluation merely involved finding the average rating given by the participants to each component of the workshop.

The bar graph was contructed by drawing a vertical axis to represent "DEGREE OF HELPFULNESS" and a horizontal axis to represent "ACTIVITY". Marks were made on the vertical axis to designate the numbers used as ratings and marks were made on the horizontal axis to designate the different activities. These marks were labeled with the appropriate activity or rating and the average rating for each activity was plotted. In the manual we've included a copy of one of the bar graphs.

III. Policy Questionnaire[2]

The results of the policy questionnaire were found entirely by determining percentages and averages. The questionnaire contained three sections. The tabulation techniques used for each are detailed below:

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[2] The policy questionnaire was administered in connection to other research which is being conducted by ACCD. Though it is not part of our short-term training project, its results are very significant to anyone concerned with self-advocate participation in VR agencies.

A. In Section I, the VR people were asked to detail the methods their agency uses to communicate with consumers, the frequency of use of each method, and the effectiveness of each method. We made a chart listing all possible answers offered on the questionnaire. We then went through the questionnaires and marked each answer down in the corresponding place on my chart. Next, we determined the percentage of respondants who answered "Yes" to indicate that the method in question is used by the agency. We, then, found the percentages of respondants answering that the method is used weekly, is used monthly, is used quarterly, or "Other". Finally, we did the same thing---i.e., found percentages---for the different ratings of effectiveness. These percentages are found by dividing the number of people giving a particular answer to a question by the number of people responding to that question and, then, multiplying the answer by 100%. For example:

$$\frac{\text{5 people answering "Very Good"}}{\text{25 who answered that question}} \times 100\% = 20\%$$

There was a section on the questionnaire in which the VR people could give any methods used by their agencies not included previously on the questionnaire. We just listed these methods separtately.

B. Section II concerned an "Assessment of Consumer Input to Agency". Several areas in which consumer input might be sought were listed and the respondant was asked to rate the effectiveness of consumers in offering input in each area as being "excellent," "good," "fair," "poor," or "input not sought". In tabulating the results for this section, we simply tallied up the number of the different responses for each input area. Since the questionnaire itself assigned numbers to each of these designations, we were able to find a total score for each input area, divide this total by the number of people who answered that question and, thereby, determine an average assessment score for the area in question.

C. Section III was a little more difficult. It consisted of four questions. Question 1 asked the respondant to explain how the agency selects consumers to participate in policy consultation. The responses to this question were difficult to score for they were in the form of short essay answers rather than the quantitative answers required on the rest of the questionnaire. Therefore, we first had to come up with some reasonable categories of responses that one might expect to the question in order to assess the frequency with which any particular kind of answer was given. Once these had been determined, we found the percentage of the total number of responses that fit into each of the categories.

Question 2 asked the respondant to rate the effectiveness of the method named in the first question. We divided the questionnaires into categories and made a chart of how many in each category rated the method as working "very well", "well", "fairly well", or "not well". These designations were numbered on the questionnaire so it was easy to find an average effectiveness score for each category of selection menthod.

Question 3 asked the VR people to rate the performance of the individuals selected to offer consumer input by having the respondant rate the extent to which each of several statements apply to the situation existing in the agency. As in the case of Question 2, the answers to this question are dependent on the method of selection named in the first question. Therefore, we tabulated the responses to each statement by the original categories. An average performance score was found for each statement rated by those VR people whose selection method fell in a particular cateogry. (Once again, tabulation was aided by the fact that the three possible ratings listed on the questionnaire were numbered).

Question 4 asked the VR people to rank several methods in the order of how effective they thought the methods would be in enhancing the level of consumer effectiveness in policy consultation. Since these responses were not directly dependent on the answer to Question 1, all questionnaires were tabulated as one group---i.e., it was not necessary to break the questionnaires down into the categories used for the other questions in this section. The number rankings given to each method were added up and divided by the number of respondants. This gave the average ranking for each method. In the report of the results, the methods were listed in order going from the method having the lowest average ranking indicating that it was considered to be the most effective to the method having the highest average ranking indicating that the respondants thought it would be the least effective.

KNOWLEDGE OF SELF-HELP GROUPS TEST

Please circle the letter of the most appropriate response.

1. Chapter 25 of the Rehabilitation Services Manual requires state agencies to "develop a formal program for receiving and considering the views" of which of the following?

    a. providers of services to disabled persons
    b. recipients of such services
    c. others active in rehabilitation
    d. all of the above

2. Chapter 25 has its foundation in which of the following?

    a. an Executive Order signed by then-President Nixon in 1973
    b. the Rehabilitation Act of 1973, as amended
    c. a collaborative agreement between RSA and CSAVR
    d. a regulation promulgated by the Secretary of HEW

3. The year of publication of Chapter 25 was

    a. 1973
    b. 1974
    c. 1975
    d. 1976

4. Chapter 25 requires all state VR agencies to

    a. adopt the consumer-involvement plan it provides
    b. develop its own written plan for public participation
    c. submit a plan for public participation to its state legislature on or before 31 October 1979
    d. submit a written plan to RSA for approval on or before 30 June 1979

5. The plan to be developed pursuant to Chapter 25 relates most to

    a. policy-consultation in rehabilitation
    b. delivery of services by state agency personnel
    c. provision of services by agency-assisted facilities
    d. relations between the agency and state consumer groups

6. Advisory committees are required by Chapter 25 to be

    a. established and functioning by 1 July 1979
    b. composed of state and regional councils to maximize input from grass-roots levels
    c. comprised of individuals selected in consultation with consumer organizations
    d. considered as one mechanism for consumer involvement

7. Self-Help groups are primarily interested in

   a. offering services to disabled people and influencing policies of state agencies such as divisions of rehabilitation
   b. operation of peer counseling and hot-line services
   c. technical assistance and consultation on barrier removal technology and devices
   d. adult and continuing education for disabled people

8. Differences between agency personnel and disabled persons would most likely be caused by which of the following?

   a. divergent views of bureaucracy
   b. differenct political philosophies
   c. differenct views of section 504
   d. divergent educational backgrounds

9. Perhaps the most serious problem in implementing effective consumer involvement in VR is

   a. funding consumer involvement programs and activities
   b. inadequate training for consumer advisors about VR policies and programs
   c. provision of supportive services, including attendant care and transportation, for consumer advisors
   d. securing meaningful representation of consumers in the state

10. The single most effective mechanism for VR personnel interested in influencing Self-Help groups would be to

   a. write and/or phone the group's members
   b. lecture at one of the group's meetings on the role and functions of VR
   c. attend several meetings of the group, coming to understand it as he helped them understand VR
   d. distribute to the group's members copies of legislative and regulative mandates affecting VR

PLEASE RETURN THE FINISHED TEST TO YOUR GROUP LEADER. THANK YOU.

Key: Knowledge of Self-Help Groups Test

1. D. The importance of this question is that it reaches knowledge that Chapter 25 involves participation of disabled people and other concerned persons and groups.

2. B. This question taps the fact that Chapter 25 has a legislative and legal basis.

3. C. The basic point is that almost three full years have elapsed since its publication.

4. B. The agency can choose from among a number of possible alternatives.

5. A. This is a policy more than a service issue.

6. D. Advisory groups, while the most common mechanism to be adopted, is only one possibility.

7. A. Self-help groups generally offer services and attempt to influence agency policy.

8. A. Disabled people in self-help groups tend to view bureaucracy as a change agent---a force for change---and to perceive lack of change as a central problem; agency personnel, on the other hand, rarely view the problem as bureaucratic response to change but rather as bureaucratic response to procedural demands. Seen differently, self-help group members tend to want VR to stimulate social change; VR personnel, on the other hand, are more concerned with meeting legislative, regulative, and administrative mandates with limited resources and within short time periods. The difference is central: it is deeper and more pervasive than are the political, educational, or section 504 divergences between agency personnel and disabled activists.

9. D. For consumer involvement to be effective, a wide range of advocacy and self-help groups must have in choosing representatives.

10. C. To influence the group, the VR representative must understand it as well as he wants its members to understand VR. Only in this way will the two come to a mutual agreement and sharing of goals.

PARTICIPANT EVALUATION QUESTIONNAIRE

Read all questions on both sheets before answering questions. Please circle the letter of the most appropriate response for the multiple-choice questions that follow. On the open-ended questions, write in your answers. Thank you.

1. With respect to informing me of the purpose and nature of the workshop and helping me to decide whether to come, the preconference mailings were

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments: ______________________________

   ____

2. The lectures presented information which was for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments: ______________________________

   ____

3. The small-group sessions were for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments: ______________________________

   ____

4. The format of the conference (mix of lectures, workshops, scheduling of events, consumer presentations) was for me

   a. Very balanced and stimulating
   b. Generally balanced and stimulating
   c. Not particularly balanced and stimulating
   d. Not at all balanced and stimulating

   With respect to format, I would have preferred to see:

   ____

   ____

5. The consumer presentations were for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments:

6. The "Guide to Self-Help Groups and Advocacy Organizations" was for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments:

7. The "Profiles in Action," in the Guide, were for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments:

8. Observing the self-help group meeting last night was for me

   a. Very helpful
   b. Generally helpful
   c. Not particularly helpful
   d. Not at all helpful

   Comments:

9. What I liked most about this workshop was:

10. What I liked least about this workshop was:

ON THE REVERSE OF THIS SHEET, ADD ANY COMMENTS YOU HAVE FOR ACCD ON PLANNING FUTURE WORKSHOPS. THEN PLEASE RETURN THIS QUESTIONNAIRE TO THE ACCD WORKSHOP COORDINATOR BEFORE YOU LEAVE. THANK YOU.

*a number indicates the number of times that answer was incorrectly given; a "C" indicates the correct answer.

IV. Item analysis of errors*

A. Pre-test

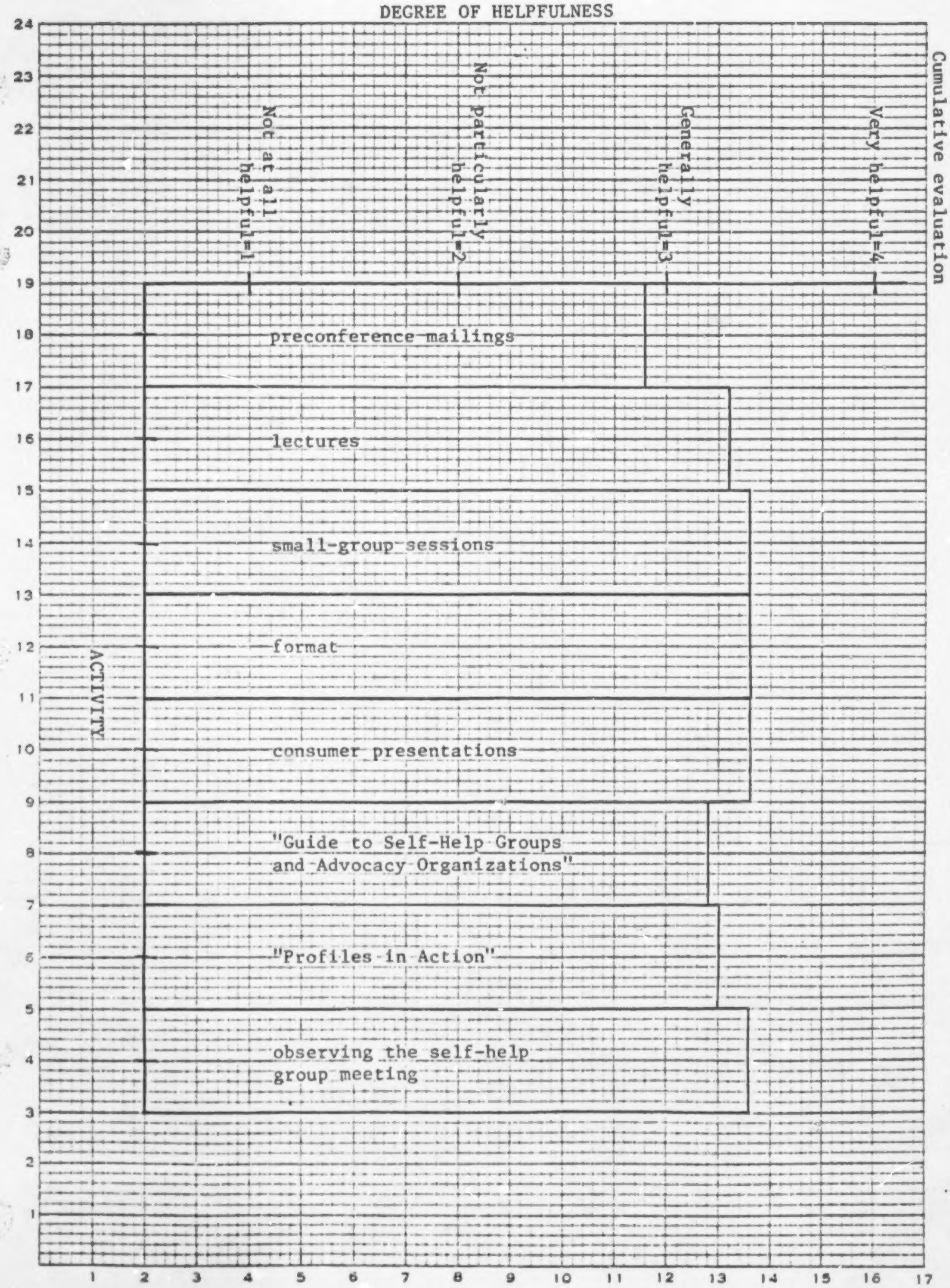
Question	a.	b.	c.	d.	Total
1	0	4	1	C	5
2	0	C	0	3	3
3	2	1	C	8	11
4	0	C	0	2	-2
5	C	1	0	4	5
6	1	0	3	C	4
7	C	3	0	1	4
8	C	0	2	3	5
9	1	7	0	C	8
10	0	0	C	0	0
					47

The average number of errors on each question=4.7
Questions 3, 9, 1, 5, and 8 missed more frequently than the average.

B. Post-test

Question	a.	b.	c.	d.	Total
1	0	1	0	C	1
2	0	C	0	0	0
3	0	2	C	2	4
4	1	C	0	0	1
5	C	0	0	5	5
6	0	0	0	C	0
7	C	0	0	0	0
8	C	0	0	2	2
9	1	7	0	C	8
10	0	0	C	0	0
					21

The average number of errors on each question=2.1
Questions 9, 5, and 3 missed more frequently than the average.


DEGREE OF HELPFULNESS
Cumulative evaluation
Not at all helpful=1
Not particularly helpful=2
Generally helpful=3
Very helpful=4
ACTIVITY
preconference mailings
lectures
small-group sessions
format
consumer presentations
"Guide to Self-Help Groups and Advocacy Organizations"
"Profiles in Action"
observing the self-help group meeting
24
23
22
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Dear Agency Representative:

As you know, ACCD is deeply concerned with identifying and facilitating methods and techniques for improving and enhancing consumer involvement in rehabilitation policy, making and service delivery.

Recently, Tufts University--Research & Training Center #7 conducted a nationwide survey of state agencies to discover what techniques the state agencies were using to effect the kinds of consumer involvement called for in Chapter 25 of the Rehabilitation Services Manual. Tufts' survey was comprehensive and is yeilding important results. But it did not permit in-depth penetration on a number of critical issues.

We're asking you to take a few moments to help us probe these issues. As a state agency director or a senior policy official, you are in a position to assess and evaluate what is happening---and what is needed. It is that knowledge we want to tap.

Completing the questionnaire will take only a few moments of your time. In conjunction with other data, however, it may save all of us months and even years in reaching goals we share.

Thank you.

Sincerely yours,

Frank G. Bowe, Ph.D.
Director

Rita A. Varela, M.A.
Coordinator

CONSUMER INVOLVEMENT IN POLICY CONSULTATION QUESTIONNAIRE

This questionnaire contains three series of questions. The first focusses upon which methods of communicating with members of the agency's constituency your agency uses, with that frequency, and with what results. The second asks you to rate the effectiveness of consumer input along a continuum of areas. The third focusses upon selected issues on enhancing consumer involvement, including selection of consumer advisors, effectiveness of outreach strategies, and options for improving the effectiveness of consumer involvement.

I. Methods and Frequency of Communication With Consumers

METHODS	USED BY OUR AGENCY (Yes, No)	FREQUENCY OF USE (Weekly, monthly quareerly, other)	EFFECTIVENESS FOR AGENCY (Very good, good, fair, poor)
Consultants			
Advisory bodies			
Public hearings			
Questionnaires			
Meetings with groups or organizations			
Attending meetings of groups			
Newsletters published by groups			
Telephone calls			
Other (specify)			

II. ASSESSMENT OF CONSUMER INPUT TO AGENCY

Below is a listing of areas in which you might seek consumer input. Please circle the number best corresponding to your assessment of how effective consuemrs in your state have been to date in offering such input.
KEY: 1=Excellent; 2=Good; 3=Fair; 4=Poor; 5=Input not sought.

1.	Evaluation of agency program services	1	2	3	4	5
2.	Program planning and development	1	2	3	4	5
3.	Legislative and budget proposals	1	2	3	4	5
4.	Accessibility of agency facilities	1	2	3	4	5
5.	Client surveys and studies	1	2	3	4	5
6.	Public awareness of agency program	1	2	3	4	5
7.	Training agency personnel	1	2	3	4	5
8.	Implementing state White House Conference on Handicapped Individuals recommendations	1	2	3	4	5
9.	Interagency coordination of services	1	2	3	4	5
10.	Agency employment of disabled people	1	2	3	4	5
11.	Establishing special facilities and programs (e.g., independent living)	1	2	3	4	5
12.	Research priorities and assessment	1	2	3	4	5

III. ENHANCING POLICY CONSULTATION

1. How do you select consumers to participate in policy consultation?

____

____

2. How well does that approach to selection appear to work? Circle the number corresponding to your assessment.

   1. Very well
   2. Well
   3. Fairly well
   4. Not well

III. ENHANCING POLICY CONSULTATION

1. How do you select consumers to participate in policy consultation?

2. How well does that approach to selection appear to work? Circle the number corresponding to your assessment.

   1. Very well
   2. Well
   3. Fairly well
   4. Not well

3. How would you rate the performance of the individuals selected to offer consumer input in establishing and maintaining effective two-way communication between the agency and its constituent groups? For each statement below, circle the number corresponding to your judgment.
KEY: 1=Very applicable; 2=Somewhat applicable; 3=Not applicable

A.	Consumer advisors tend to communicate only to others of the same disability	1	2	3
B.	Consumer advisors tend to communicate information too late for effectiveness	1	2	3
C.	Consumer advisors tend to communicate information in a manner that confuses more than clarifies issues	1	2	3
D.	Consumer advisors tend to fail to communicate to others	1	2	3
E.	Consumer advisors tend to communicate only among themselves or among "leaders"	1	2	3

For each "1" circled, please give a brief explanation of why you feel the statement reflects the situation in your state. Use the space to the right of each statement to respond.

4. Below are some methods for enhancing the level of consumer effectiveness in policy consultation. Please rank order these methods, granting a "1" to the method you think will be most effective, a "2" to the method you think will be second most effective, and so forth.

___ Statewide conference on selected issues in rehabilitation.

___ Statewide conference on how to achieve an impact upon policy-making in public agencies such as rehabilitation.

___ Statewide conference on how to organize a group effectively.

___ Statewide conference on how to be a leader and a follower.

___ A central office liaison with consumer groups.

___ A newsletter specifically for consumers.

___Election by consumers of consumer advisors to agency.

SELF-HELP GROUPS WORKSHOP: POLICY QUESTIONNAIRE
(Summer 1978)

42 State Agency Representatives completed questionnaire

I. Methods and Frequency of Communication with Consumers

Method	Used by agency	Frequency of use	Effectivenes
Consultants	62% Yes	Weekly: 21% Monthly: 8% Quarterly: 17% Other: 54% (as needed, on-going, etc.)	Very Good: 33 Good: 54% Fair: 8% Poor: 5%
Advisory bodies	90% Yes	W: 0% M: 26% Q: 55% O: 18% (annually, bimonthly, as needed, etc.)	VG: 40% G: 40% F: 14% P: 6%
Public Hearings	44% Yes	W: 0% M: 0% Q: 12% O: 88% (annually, twice a year, used for 504, etc.)	VG: 12% G: 29% F: 35% P: 24%
Questionnaires	65% Yes	W: 4% M: 4% Q: 0% O: 92% (each client, post VR center, periodically on special issues, annually, etc.)	VG: 8% G: 42% F: 46% P: 4%
Meetings with groups or organizations	93% Yes	W: 3% M: 29% Q: 16% O: 52% (occaisionally, when asked, as needed, etc.)	VG: 19% G: 67% F: 14% P: 0%
Attending meetings of groups	92% Yes	W: 6% M: 25% Q: 14% O: 55% (as indicated, when scheduled by group, periodically, etc.)	VG: 15% G: 62% F: 23% P: 0%

Newsletters published by group	74% Yes	W: 4% M: 50% Q: 27% O: 20% (bi-monthly, semi-annually, etc.)	VG: 4% G: 41% F: 44% P: 11%
Telephone calls	82% Yes	W: 20% M: 17% Q: 3% O: 60% (on-going, daily, frequently, as needed, seldom, etc.)	VG: 17% G: 62% F: 14% P: 7%

Other (each mentioned by one person):

Agency office visits	Monthly	Very goo
Task forces	Quarterly	Very good
Peer review committees and grants	3/year	Very goo
Participate with consumers in large meetings--eg. Governor's Conference on the Handicapped	About yearly	Good
Complaint hearings by CAP project	---	Fair to poor
Annual Governor's Committee Recognition Banquet	Annually	Fair to poor
NRA "Saint" stipends to attend annual Saint NRA meeting	Annually	Good
Client-consumer advocacy project	On-going	Very goo
503/504 seminars	Quarterly	Very good
Governor's Steering Committee	Monthly	Very goo

II. Assessment of Consumer Input to Agency

(Effectiveness: 1=excellent; 2=good; 3=fair; 4=poor; 5=input not sought)	Average effectiveness score
1. Evaluation of agency program services	3.14
2. Program planning and development	3.14
3. Legislative and budget proposals	2.77
4. Accessibility of agency facilities	2.66
5. Client surveys and studies	3.08
6. Public awareness of agency program	3.21
7. Training agency personnel	3.44
8. Implementing state White House Conference on Handicapped Individuals recommendations	3.10
9. Interagency coordination of services	3.41
10. Agency employment of disabled	2.71
11. Establishing special facilities and programs (eg. independent living)	2.95
12. Research priorities and assessment	4.02

III. Enhancing Policy Consultation

1. Method of selecting consumers to participate in policy consultation.
In tabulating results, it was necessary to set up the following categories of possible answers:

Selected by consumers	Selected by VR staff	Input from both	Other*
5%	40%	43%	12%

2. Effectiveness of method

	Selected by consumers	Selected by VR staff	Input from both
Works very well	100%	18%	39%
Works well	0%	40%	39%
Works fairly well	0%	24%	22%
Does not work well	0%	18%	0%

---

* Responses included in this category consist almost entirely of responses which were too vague to determine the method used. Therefore, these were not considered in questions 2 and 3.

3. Rating performance of individuals selected to offer consumer input.

(1=Statement very applicable; 2=Statement somewhat applicable; 3=Statement not applicable.)

	1	2	3
When selected by consumers:			
A. Consumer advisors tend to communicate only to others of the same disability	0%	100%	0%
B. Consumer advisors tend to communicate information too late for effectiveness	0%	0%	100%
C. Consumer advisors tend to communicate information in a manner that confuses more than clarifies issues	0%	50%	50%
D. Consumer advisors tend to fail to communicate to others	0%	0%	50%
E. Consumer advisors tend to communicate only among themselves or among "leaders"	50%	50%	0%
When selected by VR staff:			
A. ...only to others of the same disability.	25%	44%	31%
B. ...too late for effectiveness.	13%	56%	31%
C. ...in a manner that confuses.	6%	38%	56%
D. ...fail to communicate.	31%	25%	44%
E. ...only among themselves or among "leaders"	38%	56%	6%
When input comes from both:			
A. ...same disability.	29%	42%	29%
B. ...too late.	0%	53%	47%
C. ...in a manner that confuses.	0%	47%	53%
D. ...fail to communicate.	0%	47%	53%
E. ...only among themselves or among leaders.	12%	47%	41%

4. Rank ordering of how effective various methods might be in enhancing the level of consumer effectiveness.

	Average ranking
1. A central office liaison with consumer groups	2.2
2. Election by consumers of consumer advisors to agency.	2.73
3. Statewide conference on how to achieve an impact upon policy-making in public agencies such as rehabilitation.	3.27
4. Statewide conference on selected issues in rehabilitation.	3.75
5. Statewide conference on how to organize a group effectively.	3.95
6. A newsletter specifically for consumers.	4.18
7. Statewide conference on how to be a leader and a follower.	5.61

SECTION V

Originally, we issued fifty statewide Guides to Advocacy Organizations and Self-Help Groups for distribution to state agency VR commissioners during the workshops. We are in the process of updating those lists in order to publish a nationwide guide.

This section includes the following narrative material developed for those directories:

- "A Reason for Knowing," by Saul Alinsky
- Profiles in Action
- Organizational Outreach Form

A Reason for Knowing

"One of the great problems in the beginning of an organization is, often, that the people do not know what they want. Discovering this stirs up, in the organizer, that inner doubt shared by so many, whether the masses of people are competent to make decisions for a democratic society. It is the schizophrenia of a free society that we outwardly espouse faith in the people but inwardly have strong doubts whether the people can be trusted. These reservations can destroy the effectiveness of the most creative and talented organizer. Many times, contact with low-income groups does not fire one with enthusiasm for the political gospel of democracy. This disillusionment comes partly because we romanticize the poor in a way we romanticize other sectors of society, and partly because when you talk with any people you find yourselves confronted with clichés, a variety of superficial, stereotyped responses, and a general lack of information. In a black ghetto if you ask, "What's wrong?" you are told, "Well, the schools are segregated." "What do you think should be done to make better schools?" "Well, they should be desegregated," "How?" "Well, you know." And if you don't know, then a lack of knowledge or an inability on the part of the one you are talking to may show itself in a defensive, hostile reaction: "You whites were responsible for the segregation in the first place. We didn't do it. So it's your problem, not ours. You started it, you finish it." If you pursue the point by asking, "Well, what else is wrong with the schools right now?" You get the answer, "The buildings are old; the teachers are bad. We've got to have change." "Well, what kind of change?" "Well, everybody knows things have to be changed." That is usually the end of the line. If you push it any further, you come again to a hostile, defensive reaction or to withdrawal as they suddenly remember they have to be somewhere else.

The issue that is not clear to organizers, missionaries, educators, or any outsider, is simply that if people feel they don't have the power to change a bad situation, then they do not think about it. Why start figuring out how you are going to spend a million dollars if you do not have a million dollars or are ever going to have a million dollars - unless you want to engage in fantasy?

Once people are organized so that they have the power to make changes, then, when confronted with questions of change, they begin to think and to ask questions about how to make the changes. If the teachers in the schools are bad then what do we mean by a bad teacher? What is a good teacher? How do we get good teachers? When we say our children do not understand what the teachers are talking about and our teachers do not understand what the children are talking about, then we ask how communication can be established. Why cannot teachers communicate with the children and the latter with the teachers. What are the hangups? Why don't the teachers understand what the values are in our neighborhoods? How can we make them understand? All these and many other perceptive questions begin to arise. It is when people have a genuine opportunity to act and to change conditions that they begin to think their

-more-

problems through - then they show their competence, raise the right questions, seek special professional counsel and look for the answers. Then you begin to realize that believing in people is not just a romantic myth. But here you see that the first requirement for communication and education is for people to have a reason for knowing. It is the creation of the instrument or the circumstances of power that provides the reason and makes knowledge essential."

Saul D. Alinsky. Rules for Radicals. New York: Vintage Books, 1972, pp.104-106.

PROFILES IN ACTION

A series of papers illustrating the ways some people who have disabilities are facilitating the habilitative process.

THE NEED:

Lack of adequate housing has caused many elderly and disabled people to compromise their futures and restrict their vocational choice, and in too many instances has forced them prematurely into institutional residences.

National Center for a
Barrier-Free Environment

THE GROUP:

Handicap Housing Service, Inc.
230 Metro Square Building
7th and Robert Street
St. Paul, Minnesota 55101

Contact: Mary O'Hara
Staff Director
612/222-1813

THE GOAL:

Coming Home

o o o o

Even if one does have independent living skills, finding accessible housing can be a major ordeal. Plans for renovating houses abound -- in libraries, yes; but not always where one can get to them and talk about them with a contractor or landlord.

Handicap Housing Services, Inc. (HHS), a Minnesota group, was established as a result of frustration among consumers and of their need for usable, liveable housing. The group receives funds from the Department of Housing and Urban Development, as well as other public sources. Their approach, though simple and straightforward, is quite unique: After initial consultation with potential buyers, HHS acquires suitable property, prepares designs in accordance with the needs of the family, supervises the rehabilitation of the property to ensure that it will meet or exceed all applicable codes, and sells it to the buyers.

HHS staffers receive a variety of calls each day from disabled people and their families who need housing, who want to know about what grants are available for renovations, and who have complaints about architectural barriers. The organization has received a contract from the Minnesota State Council for the Handicapped to produce a Housing Resource Book which will help persons throughout the state cope more effectively with these issues. In addition, HHS has worked with various state agencies, and with legislatures as well, to eliminate some of the obstacles which keep disabled citizens from participating fully in society.

THE NEED:

> Perhaps the warning to "assume nothing" about a person with a disability until evidence and not inference holds sway can become a motto, a sobering reminder of the importance of holding those forces at bay that press toward "knowing" a person where, in fact, knowledge is lacking.
>
> Beatrice A. Wright
> Psychology Department
> University of Kansas

THE GROUP:

Center of Handicapper Affairs
1026 E. Michigan Avenue
Lansing, Michigan 48912

Contact: Leonard P. Sawisch
Executive Director
517/485-5887
Voice or TTY

THE GOAL:

Friendship -- Action -- Change

o o o o

They call themselves handicappers, people who define their own degree of abilities. And, according to Leonard Sawisch, executive director of the Center, "handicappers are about the business of helping handicappers."

The Center of Handicapper Affairs, a peer support agency in Lansing, is funded partly through an HEW grant administered by the Michigan Bureau of Rehabilitation. Its chief activity is information referral. The staff compiles "who-what-where-how" data on housing, transportation, accessibility, civil rights, and various other concerns, and will publish a resource directory and an Access Lansing guide.

The Center is actively involved in outreach. Through its rap sessions, seminars, and one-to-one peer contacts, it provides opportunities for handicappers to interact, share, plan, and grow. Their newsletter keeps hundreds of citizens informed of major activities in the Lansing area and throughout the state. In addition, they have produced a television series entitled "We All Live Here."

That title vividly reflects the handicapper philosophy. In a letter distributed to the delegates of the White House Conference of Handicapped Individuals, the founders of the Center wrote: "We have all said or thought, 'Thank God I'm not mentally retarded or deaf or crippled or blind or deformed' each from our own sheltered perspective. When we tear down these internal walls, we will become the most powerful political and social movement in decades."

THE NEED:

> "Architectural and transportation barriers are a major obstacle to the mobility of the handicapped, affecting all phases of life. Lack of accessibility to the work place and to public transportation is the problem many qualified individuals face in their attempts to achieve their employment goals."

Patricia J. Thoben,
U.S. Civil Service Commission

THE GROUP:

Mobility On Wheels, Inc.
1712 Glendon Avenue
Norfolk, Virginia 23518

Contact: Wm. Pat White
President

THE GOAL:

Access -- for ALL Citizens

o o o o

Like most consumer groups, MOW has many interests. There's one project, however, which they're especially proud of: their accessibility campaign in the Tidewater area of Virginia.

MOW set out to survey all public gathering places in the 4-city Tidewater area of Southeast Virginia (Portsmouth, Norfolk, Chesapeake, and Virginia Beach). Though this effort began as an all volunteer project, they now have eleven CETA-paid inspectors who go into the community. CETA also pays the salary of the project director and of a clerk. As part of the survey process, the inspector asks the individuals visited whether they intend to improve accessibility and if so, whether they would like technical assistance in order to make establishments accessible. According to Mr. William (Pat) White, over fifty individuals have accepted MOW's offer so far. "We expect 8-10,000 entries in the Guide we plan to issue," said Mr. White, MOW has a membership list of over 500 people. Their newsletter keeps constituents and others informed on State and national legislation, programs, and coming events. Their accessibility survey, publications, and legislative advocacy shows their commitment to being active, concerned citizens, and that is how business and community leaders have come to see them.

THE NEED:

If the time that has been devoted to discussing avoidance of the /¯Rehabilitation Act of 1973_7 or debating its financial implications could be applied instead to innovative thinking regarding compliance with the Act, then perhaps by next year at this time the phrase "employ the handicapped" might be more than just a motto clouded by uncertainty and controversy.

Carol S. Carter
Affirmative Action Specialist,
Pennsylvania State University

THE GROUP:

Disability Rights Center
1346 Connecticut Avenue, NW
Washington, D. C. 20036

Contact: Debby Kaplan
202/223-3304

THE GOAL:

Keeping Tabs on the System

o o o o

How effective are our regulations mandating affirmative action in Federal hiring practices? This is what the Disability Rights Center is trying to find out as it studies the implementation of section 501 of the Rehabilitation Act of 1973.

Currently, the Center is focusing on twelve Federal agencies. Project staffers survey the agencies through a series of statistical inquiries, interviews, barrier removal surveys, and affirmative action plan analyses. Debby Kaplan, executive director of the Center, finds that many of the individuals assigned to coordinating their agency's affirmative action program are not quite sure how to maximize their time and resources, and welcome a chance to talk with DRC interviewers. Thus, though the Center is engaged in a research project, it is involved in awareness training and advocacy as well.

The Disability Rights Center will be publishing its findings and recommendations soon, and hopes the report will serve as a catalyst to more effective affirmative action programs in Federal agencies. The most exciting aspect of the project, however, may be that it will show citizens on the state level how to monitor and facilitate compliance with affirmative action mandates.

The Center also has plans to publish two guides on how to use the newly issued complaint procedure for disabled applicants and employees of Federal agencies who are victims of disability discrimination. One guide will be written for attorneys, union representatives and other advocates. The other will be written for disabled people. The guides should be available from the Center in the fall.

THE NEED:

> "... only when we work together, the handicapped who are leaders, the handicapped who will always be dependent, the potentially handicapped child who wants to have that disability prevented and the non-handicapped adult leader ... can we continue to make even greater progress."
>
> President Jimmy Carter

THE GROUP:

Florida Council of Organizations
of the Handicapped, Inc.
5201 Lazy Lake Lane
St. Petersburg, Florida 33708

Contact: Joseph Veisz

THE GOAL:

Environmental Accessibility and Legislative Advocacy

o o o o

Florida has one of the strongest coalitions of disabled consumer groups in the United States. The Florida Council of Organizations of the Handicapped has affiliate groups throughout Florida, and a voice in Tallahassee -- the State capital.

FCOH keeps someone in Tallahassee every day that the legislature is in session. But the legislature also hears from the FCOH people back home, who send in 300 to 400 letters, cards, and mail-o-grams during each session. FCOH tries to ensure that legislators serving on important committees hear from their disabled constituents. According to Joe Veisz, one of FCOH's best known advocates, "Public apathy is so widespread that seven or eight letters to the right senator can swing a vote."

FCOH has been very successful in fighting for increased VR funding, certain important categorical programs, civil rights bill, and the Early Intervention Program to provide better pre- and post-natal care. The Early Intervention Program was a high priority issue for professionals and consumers alike. "You can't do it all from the State Capitol," says Joe. "You have to have people -- people who are organized, who get together with friends in local groups and talk about these issues. The guy in the legislature will want to know if there are folks back home who approve of the way he's spending their money."

=

THE NEED:

> "Why wait until the applicant is severely impaired by the multiple handicapping effects of long-term, unattended disability?"

George N. Wright
American Rehabilitation
Counseling Association

THE GROUP:

National Paraplegia Foundation
Greater Milwaukee Area Chapter
3575 North Oakland Avenue
Milwaukee, Wisconsin 53211

Contact: Ellen Daly
Executive Director
414/332-3930

THE GOAL:

Preventing Irreparable Damage

o o o o

The newly disabled individual often feels alone, frightened, and very uncooperative. The folks at GMAC understand the plight of the person who must suddenly adjust to a spinal cord injury. They've been through that mill, and have uncovered two vital facts: First, that you can adjust. Second, that the sooner you get out of the hospital bed and begin therapy, the easier it is to prevent additional physical problems.

The first few days in the hospital can be crucial to the physical and emotional welfare of someone newly disabled with a spinal cord injury. GMAC is often asked, by family members of disabled individuals, to send a volunteer to the hospital and visit with the newly injured person and family. The GMAC staff has been running this peer support program for over ten years, and generally try to match the the volunteer and referral according to such characteristics as age, sex, marital status, and profession.

These volunteers can supply much more than a sympathetic ear. They know their business, and can often express critically important opinions as to whether the newly injured person is getting proper medical attention. Insurance companies, who have a vested interest in preventing severity and getting people back to work, have learned to trust the GMAC volunteers. And so have the people they visit, who, years later, often say, "I couldn't have made it without you."

THE NEED:

> "... it is probably technically possible to teach anyone who is reasonably alert and has some movement to work. The problem is the jobs."
>
> Report of the Comprehensive Service Needs Study

THE GROUP:

Resources for Independent Living
3540 42nd Avenue
Sacramento, California 95824

Contact: David Pout
(916) 422-1733

THE GOAL:

An Affirmative Action

o o o o

According to David Pout, Peer Counselor of the Resources for Independent Living, there are a lot of myths about the disabled job seeker, and you can't always correct them by sending out "Hire the Handicapped" booklets.

RIL's job advocacy project is highly personal, innovative, and effective. RIL trains disabled persons to serve as job advocates. They visit prospective employers, collect data on hiring practices, and find out the organizations' labor needs. What jobs have to be done, what skills and abilities are required? In addition, advocates talk to the employers, telling them about studies showing the disabled workers have good performance records and low turnover rates.

RIL has worked with some of the largest enterprises in California. The key to RIL's effectiveness is that its policy of establishing one-to-one relationships with employers. After learning the company's needs, RIL searches through its lists to find suitable candidates. RIL contacts them, and often helps them through the application and orientation process. This sort of outreach and follow through reinforces the idea that disabled citizens can be good advocates, good workers, and good friends.

Date of Entry for Contact Data: ___/___/___

ORGANIZATIONAL OUTREACH FORM

I. NAME OF ORGANIZATION ______________________________

MAILING ADDRESS ______________________________

____

ZIP ________

TELEPHONE NUMBER(S) (___)________ (___)________

CONTACT PERSON(S) ____________ ____________

II. OFFICERS

TITLE	NAME	TERM EXPIRES	TELEPHONE NUMBER
________	________	_____	(___)________
________	________	_____	(___)________
________	________	_____	(___)________
________	________	_____	(___)________

III. PRINCIPAL ACTIVITIES, PROJECTS, PUBLICATIONS

____

____

IV. LOG OF CONTACTS

1. DATE: ___/___/___ PURPOSE AND OUTCOMES: ________

MEANS: ___LETTER
___PHONE
___MEETING
___ON-SITE VISIT
___OTHER

____

____

____

(Enter subsequent contact data on following sheets or forms)

APPENDIX C

ACCD'S FOLLOW-UP EVALUATION SURVEY

ACCD's follow-up survey was modeled after TEK, the Training Evaluation Kit developed by the Rehabilitation Research and Training Center at the University of Oregon.

RESULTS

Instruction

The Follow-up Evaluation Questionnaire seeks to assess the impact of the ACCD workshop on the Role of Self-Help Organizations in Vocational Rehabilitation. Your feedback will help our staff evaluate the effectiveness of the workshop and improve future programs. We appreciate your cooperation in this effort.

A Baseline for Comparison

In completing this questionnaire, we would like you to compare your agency's perspectives and activities before the workshop and after the workshop, and to determine whether the workshop contributed to any changes. Therefore, we would like you to check Yes only when you feel the workshop effected a change in the items listed.

PROFESSIONAL DEVELOPMENT

1. Since the workshop, has the number of materials you have read concerning consumer involvement and self-help organizations increased?

Yes 73.9%
No 26.08%
No response ____

2. Since the workshop, has the number of materials which you have read and that were written by disabled citizens and/or published by self-help groups increased?

Yes 52.17%
No 47.82%
No response ____

3. Since the workshop, has the number of conferences, meetings, or seminars on self-advocacy which you or your staff has participated in increased?

Yes 21.73%
No 73.91%
No response ____

4. Since the workshop, has the number of self-advocacy related proposals, research efforts, staff memorandums, and/or reviews of policy statements within your department increased?

Yes 39.13%
No 52.17%
No response 8.69%

5. Since the workshop, has the number of professional contacts you have had in your own or other states and which have been related to topics covered in the workshop increased?

Yes 69.56%
No 30.43%
No response ____

6. Since the workshop, has the amount of activity in which you have engaged related to letting others know about any of the topics covered in the seminar increased?	Yes 82.6% No 13.06% No response 4.34%

PROFESSIONAL ACTIVITY

1. Since the workshop, has the number of disabled individuals with whom you have discussed consumer involvement increased?	Yes 73.91% No 26.09%
2. Since the workshop, has the number of disabled self-advocacy groups that you have been in contact with increased?	Yes 17.39% No 73.91% No response 8.69%
3. Since the workshop, has the number of disabled individuals and self-advocacy groups that you have sought to inform about your agency's policies (through newsletters, memos, and/or direct contact) increased?	Yes 26.08% No 56.52% No response 17.39
4. Since the workshop, has the amount of time you or your staff has spent reviewing the status and effectiveness of your policy consultation plan (which was developed in response to Chapter 25 of the Rehabilitation Services Manual) increased?	Yes 60.86% No 39.14%
5. Since the workshop, has the number of disabled self-advocates or self-advocacy groups that you have sought to involve in the policy consultation increased?	Yes 34.78% No 60.86% No response 4.34%

SELF-HELP PROJECTS

1. Since the workshop, has the amount of time you have spent considering or reviewing resources relating to CIL's, peer counseling, and/or other services which could be provided through organizations run by disabled individuals increased?	Yes 60.86% No 30.43% No response 8.69%
2. Since the workshop, has the number of self-help activities which you have learned about or inquired about in your state increased?	Yes 87.82% No 47.82% No response 4.34%
3. Since the workshop, has the amount of time you or your staff has spent considering, reviewing, or planning for ways in which the resources of self-help groups can be used to augment the services now provided through your agency increased?	Yes 47.82% No 52.17%

4. Since the workshop, have the number of contracts (correspondence, meetings, consultations) you have had with representatives of self-help groups with respect to the resources of or projects sponsored by them increased?	Yes 43.47% No 52.17%
5. Since the workshop, has the amount of time you or your staff has spent in drawing up plans for utilizing the resources of self-help groups increased?	Yes 52.17% No 39.13% No response 8.69%
6. Since the workshop, have the number of proposals you have considered or discussions you have begun with representatives of self-advocacy groups to begin specific self-help projects increased?	Yes 34.78% No 56.52% No response 8.69%

MATERIALS, TOOLS, FOLLOW-UP TRAINING

1. Since the workshop, have you had a chance to use the Guide to Self-Help Groups and Advocacy Organizations?	Yes 47.82% No 47.82% No response 4.34%
2. Since the workshop, have you contacted any of the groups listed in your Guide to Self-Help Groups and Advocacy Organizations?	Yes 39.13% No 60.86%
3. Do you feel that the Organizational Outreach Form which appears in your Guide could help you and/or your agency in maintaining better contact with the various self-help groups in your state?	Yes 86.95% No 8.69% No response 4.34%
4. Have the materials distributed at the workshop helped you to share with your colleagues the concepts which were discussed at the workshop?	Yes 91.3% No 8.69%
5. Do you think there is a need for follow-up training to acquaint additional agency personnel with the role of self-help groups in vocational rehabilitation?	Yes 86.95% No 8.69% No response 4.34%

APPENDIX D

STATE OF CONNECTICUT

DEPARTMENT OF MENTAL HEALTH

NORTH CENTRAL - REGION IV
~~Cedarcrest Regional Hospital~~
~~Newington, Connecticut 06111~~

OFFICE OF THE REGIONAL DIRECTOR
233 Main Street (Suite 700)
New Britain, CT 06050

(AC 203) ~~667-3374~~
~~667-3439~~
~~666-4613~~
827-7790

February 14, 1979

Ms. Rita Varela
American Coalition of Citizens with Disabilities
1346 Connecticut Avenue, Northwest
Washington, D.C. 20036

Dear Rita:

I was very glad that ACCD was able to convene the Advisory Group on January 12, 1979. I found the meeting quite productive.

I was very impressed with the final report of Grant No. 45-P-812853-01. It was very reassuring to learn that the advice of the Advisory Committee in January of 1978 was successfully implemented by ACCD. Finding out that over one-third of the State Directors were reached personally, and many Directors of Training in departments were similarly reached was heartening. The conference participants' request for additional involvement also leads me to believe that the payoffs for short-term training will continue for some time in the future.

I would like to lend support to Dr. Bowe's strategy of continuing the same kind and method of training as was implemented during the past year. With all of the fiscal contraints on ACCD, I believe a continuation of the proven product to be the most efficient and effective use of scarce resources.

Clearly there is a lot of unfinished business from last year's sessions. So long as the ratio of $50 of dependency spending for every dollar of independence training continues, the work of the Coalition will remain incomplete. I applaud your efforts up to this point and wish you continuing success toward achieving your goals.

Sincerely,

Larry

Lawrence I. Pittinger
Regional Director

kbh
cc: File

P.S. Attached are my housekeeping papers. Please let me know if any further information is needed.

STATE OF RHODE ISLAND AND PROVIDENCE PLANTATIONS

Department of Social and Rehabilitative Services
VOCATIONAL REHABILITATION
40 Fountain Street
Providence, R.I. 02903
(401) 421-7005

August 22, 1978

Ms. Rita A. Varela
Special Projects Manager
American Coalition of Citizens
with Disabilities, Inc.
Room 817, 1346 Connecticut Avenue, N.W.
Washington, DC 20036

Dear Ms. Varela:

The recent ACCD workshop on "The Role of Self-Help Organizations in Vocational Rehabilitation" was a rich-sharing experience for me personally.

To attempt to measure that experience in connection with increased self-advocacy efforts in Vocational Rehabilitation in Rhode Island is difficult; however, since we are a small, informal State, opportunities for consumer involvement continue to be available and utilized.

For example, we have an Advisory Board to Vocational Rehabilitation with consumer participation. I am enclosing the Bylaws of that organization. We have one of twenty Client Assistance Projects in the country and that brochure is enclosed. Our Client Assistance Project has an Advisory Committee of self-help and advocacy organization individuals.

Some of our staff members do volunteer work in consumer organizations. I am on the Board of the Governor's Committee on Employment of the Handicapped, which is preparing a campaign to coordinate advocacy efforts. I am on the State Special Education Advisory Committee, along with parents and handicapped individuals. Supervisory staff have extensive input from the deaf community, organizations relating to developmental disabilities, spinal cord injured, etc. We also had a staff member as delegate to the White House Conference on Handicapped Individuals.

We will send you, as soon as available, an update on advocacy organizations in Rhode Island which is now being prepared.

We look forward to the continued sharing of our mutual concerns.

Sincerely,

Edward J. Carley

Edward J. Carley
Administrator
Vocational Rehabilitation

EJC/kfa

Enclosures

PENINSULA
HANDICAPS UNLIMITED, INC.
OFFICE ADDRESS
413 WEST MERCURY BOULEVARD
HAMPTON, VIRGINIA 23666
TELEPHONE 723-3457

ORGANIZATION MAILING ADDRESS
POST OFFICE BOX 9372
BRAIRFIELD STATION
HAMPTON, VIRGINIA 23670

October 5, 1978

Mr. Frank Bowe
ACCD Director, ACCD, Inc.
1346 Connecticut Avenue, N.W.
Room 817
Washington, D.C. 20036

Dear Mr. Bowe:

Enclosed you will find a copy of Handicaps Unlimited of Va's application for State Coilition membership in the ACCD. Due to time constraints and at Eunice Fiorito's suggestion, I have forwarded the original to Dr. Fredrick Faye (membership chairman). Eunice felt that to expedite processing and to allow time for the board to vote during the next meeting, this method would be the most efficient.

I have also enclosed copies of our recent workshop materials "Special Concerns of the Handicapped Person" with the membership application. This I think will give you much insight as to our dedications to educating Virginia's population on the unique problems of handicapped individuals.

Finally, let me take this opportunity to thank you for the excellent workshop "Training for Trainers" that I recently attended in Arlington. This was for me one of the most important events in my years of experience as an advocate.

Sincerely,

John A. Chappell, Jr.

John A. Chappell, Jr.
President of Handicaps Unlimited of Va.

JACJR:lmb

cc: Mr. Pat White
Dr. Fredrick Faye
Ms. Eunice Fiorito

P.S. Included in original application are also copies of By-Laws, News Letters, etc.

STATE OF NEVADA
DEPARTMENT OF HUMAN RESOURCES
Michael L. Melner, DIRECTOR
MIKE O'CALLAGHAN, GOVERNOR
DEL FROST, ADMINISTRATOR

REHABILITATION DIVISION

BUREAU OF VOCATIONAL REHABILITATION
KINKEAD BUILDING, FIFTH FLOOR
505 EAST KING STREET
STATE CAPITOL COMPLEX
CARSON CITY, NEVADA 89710

July 25, 1978

Rita A. Varela
ACCD - Rm. 817
1346 Connecticut Avenue N.W.
Washington, D.C. 20036

Dear Rita:

I'd like to take the time to thank you for providing me the opportunity, to become knowledgeable of Self-Help Groups and how they can contribute to the effective delivery of Vocational Rehabilitation services.

I enjoyed talking with you however briefly about some of our concerns in Nevada and I would welcome the opportunity to participate in future programs that ACCD sponsors. I felt the Berkeley Workshop was a valuable experience and I was impressed with the efforts of Jan Saunders, Mimi Duncan of CSAVR and yourself. You should be commended for keeping the group moving when things started to bog down.

I will discuss the Resource directory with others involved with rehabilitation in Nevada and relay their comments and additions to you.

I plan to attend the National Rehabilitation Engineering Conference in Washington, D.C. September 4-8 and hope to visit with you all. Till then, take care.

Sincerely,

Ron Fleck, Comprehensive Services Specialist

RF:bt

ROBERT L. BRUNELLE
COMMISSIONER

NEAL D. ANDREW, JR.
DEPUTY COMMISSIONER

STATE OF NEW HAMPSHIRE
DEPARTMENT OF EDUCATION

DIVISION OF
VOCATIONAL REHABILITATION
105 Loudon Road Bldg. No. 3
Concord, N.H. 03301
Tel: (603) 271-3121

June 30, 1978

Dr. Frank G. Bowe, Director
American Coalition of Citizens
with Disabilities, Inc.
Room 817
1346 Connecticut Avenue, N.W.
Washington, D.C. 20036

Dear Frank:

At the closing session of the ACCD conference on Self-Help Groups in Vocational Rehabilitation held in Philadelphia, Pennsylvania on June 12 and 13, 1978, you asked each of the three small groups to submit in writing their summary of the final small group session which was entitled "Formulating a Plan." Following are the points developed by our group for follow-up once participants had returned to their own Vocational Rehabilitation Agency:

> A brief poll, which I hope is accurate, revealed that four of the six states represented in our group made up of Maine, New Hampshire, Massachusetts, New York, New Jersey, and Connecticut did not currently have operating Advisory Councils with consumer representation to assist the state Vocational Rehabilitation agency in policy and procedural considerations.
>
> Regardless of the obvious individual differences between states, the group felt that immediate efforts in the areas of public relations and more importantly public education needed to be carried out specifically with the Self-Help and other consumer advocacy groups concerning Vocational Rehabilitation programs, its constraints and its needs in order to provide more effective service delivery mechanisms to the disabled consumer. Note was made of the confusion and lack of knowledge on the part of consumers regarding existing Vocational Rehabilitation programs, and that this confusion can be expected to increase with passage of proposed Federal legislation such as the Javitts Bill and its emphasis upon independent living. Arrangements for public education and training activities for both VR agency personnel as well as the consumer will need to be arranged.
>
> All participants appeared to agree that the Vocational Rehabilitation agency, in establishing an Advisory Committee, should actively seek the recommendations of self-help groups and consumer advocacy groups regarding appropriate consumer representation. Advisory members should not be the exclusive, "hand-picked" persons chosen by the state agency.

LIVE FREE OR DIE

Disability Knows No Race, Color, or National Origin - We Serve All of the Handicapped

Equal Opportunity Employer - Equal Educational Opportunities

The VR agency should make arrangements to set aside a portion of its funds to meet necessary expenditures of advisory groups and/or self-help groups being asked to participate in policy and procedural decisions of the state VR agency.

Specific training efforts need to be made by the state VR agency to be certain that staff are sensitized to the needs and concerns of self-help and consumer advocacy groups and that the state agency maintain at all times a viable means of seeking out and utilizing the recommendations of such groups.

Self-help groups need to be encouraged to educate the Vocational Rehabilitation agency as to, the mission, objective, budget needs and structure - representation of disabilities, of concern to the self-help group.

In conclusion, there was consensus that each participant would bring back to his prospective state VR Director the positive aspects of this conference and the benefit to be gained by both the state agency and the self-help group by working together on mutual concerns affecting the delivery of Vocational Rehabilitation services. It was recognized that self-help groups can be of tremendous asset to the state VR agency in bringing more meaningful and efficient programs to the disabled.

A specific recommendation is made that the ACCD prepare a follow-up survey of participating state VR agencies in perhaps three to six months to determine what plans and actions have been taken by the respective state VR agencies as a result of this meaningful conference.

Thank you for the fine effort you, your staff and consumer representatives made in making this conference possible and for the opportunity of sharing these critical concerns in an open and candid manner. I feel confident these efforts will bear rich fruit.

Sincerely,

Peter S.B. Clark
Deputy Chief of the Division

PSBC/kmf

cc: Group Members - Ronald Hanson, Maine
Michael Cassels, New Jersey
Howard Berger, New York ✓
Paul McDade, Massachusetts
Joseph Galotti, Connecticut

BOSTON SELF HELP CENTER
for people with a physical disability or chronic disease
18 WILLISTON ROAD BROOKLINE, MA. 02146 (617) 277-0080

Advocacy
Education
Counseling
Resources

June 20, 1978

Ms. Rita Varela
C/O ACCD
Rm. 817
1346 Conn. Ave., N.W.
Washington, D.C. =20036

Dear Rita:

I want to begin by sharing my sincere appreciation for the opportunity for growth you afforded both me and Boston Self Help Center in allowing me to participate in the VR-Self Help Conference. I've been mulling several comments in my head since the conference and realize some new areas in which I might approach traditional structures.

Not only did I enjoy participating in the conference and sharing our activities, but it's especially inspiring for me to talk to you, Frank, and the DIA people. My experience of the conference was very positive. It was well-planned with a balanced mix of didactic and experiential components and I particularly appreciated the role-playing exercises. Again, I wish to thank you for your vote of support in inviting me. (I sent my expense voucher in a letter to Frank.)

Ironically, many of the issues to which Frank made reference regarding the growth of self help groups were particularly timely for us. We are experiencing another organizational and funding crisis and it's helpful to recognize that these difficulties are more common. (We have a tendency to lose that perspective and to interpret too much as personal failures.) Therefore, I received an important dose of inspiration and energy from being at the conference.

Personally, I enjoy your delightful company and find your humor and dedication uplifting. We will be happy to send any amendments to the Self Help directory. This will be helpful to us in our outreach to enlist support for advocacy issues from other formal groups in Massachusetts.

Good luck in your future workshops. I'm confident that more VR-consumer involvement projects will be generated as a result of your work, judging by some feedback I received near the end of our Workshop.

I look forward to more communication in the future with you and ACCD as we proceed toward our mutual goals.

Sincerely yours:

Kate

Kate Hoffman

NAD NATIONAL ASSOCIATION OF THE DEAF
BRANCH OFFICE
445 N. PENNSYLVANIA ST., SUITE 804
INDIANAPOLIS, INDIANA 46204
PHONE 317-638-1715

GARY W. OLSEN
ASSISTANT EXECUTIVE DIRECTOR
STATE AFFAIRS

October 10, 1978

Ms. Rita A. Varela
Special Projects Manager
American Coalition of Citizens
with Disabilities Inc.
1346 Connecticut Avenue, N.W.
Room 817
Washington, D. C. 20036

Dear Rita:

Thank you for your nice letter. I appreciate your thoughtfulness and encouragement to continue our dialogue.

The workshop was very good! I enjoyed and learned much. However, I wish there were more time spent on developing the SKILLS sections. Well I guess there might be another time for this.

Enclosed is my expense sheet. Please see to it that the airfare portion is sent to National Association of the Deaf because I used their air travel card for this trip. If there are any differences that I owe the ACCD for the room and meals, please let me know.

Again, Rita, you did a great job and I appreciate ACCD considering me. I will be doing everything I can to promote ACCD's cause.

Now, let me say a few words about Frank, he has been doing G-R-E-A-T! He is an inspiration to many of us and I am sure he will bring ACCD and many handicapped people to greater heights!

Can you please send me copies of ACCD Action since last June? I want to have a complete set. Also apparently my name has been removed from the mailing list. Can you see to it that my office is added to it?

Keep up your fine work!

Am with you all!

Gary W. Olsen
Assistant Executive Director
State Affairs

PAID
OCT 12 1978
1349

P.S. Please send me a copy of Frank's open talk at the Training program.

Might visit ACCD on the 26th of this month while in D.C.

UNITED HANDICAPPED FEDERATION

1951 University Avenue
St. Paul, Minnesota 55104
645-3417
TTY 645-3418

September 29, 1978

Ms. Rita Varela
ACCD
Room 817, 1346 Connecticut Ave. NW
Washington, D.C. 20036

Dear Rita:

I would like to express my sincere appreciation to you for providing the opportunity for several leaders in the handicapped community to get together for an intensive training and learning session. In my opinion this session was one of the most productive and stimulating that I have ever been to. The issues that we discussed and involved ourselves in, as they relate to the VR agencies across the country, were of particular import as they will facilitate the growth and strength of handicapped consumers in affecting decisions in their rehabilitation process. Rehabilitation agencies will also benefit from the increased awareness that consumers will gain about how the agency functions.

I would also ask that you would extend appreciation to Frank for making all of this possible. Over the past two years I have seen that as a direct result of his conserted efforts we now have a nation wide, united, and effective tool for organizational communications.

I look forward to working together with you in the future. Again, let me congratulate you on a most successful effort.

Sincerely,

Scott W. Rostron
President

a social action organization of, by, and for handicapped people

STAVROS FOUNDATION
691 South East Street
Amherst, MA. 01002
(413) 256-0473

September 26, 1978

Frank Bowe
ACCD
Washington, D.C.

Dear Frank,

I'd like to express my thanks and appreciation for the Training for Trainers Seminar of last week. I found it extremely beneficial in providing both an over-view of the main issues and directions in the disability movement and a focus for direct state and local action. We plan to put many of the recommendations of the Training into motion in Massachusetts.

My own plans are to make a six-month road trip to visit groups and individuals who are promoting independent living throughout the country. I will be leaving in mid-October and passing through D.C., Florida, Louisana, New Mexico, Texas, California, Oregon and back throught the Midwest, especially Michigan. I'd appreciate your input as to whom I should contact.

I had a good talk with Hal Shay and I will be submitting an application for a research grant to RSA. These grants are usually for doctoral research but in this case could cover my project--a study of the various approaches to Peer Counseling taken by self-help groups around the country and the potential benefits of Peer Counseling to the State Voc Rehab systems. This would be done from my perspective as a disabled consumer and Peer Counselor. Dr. Irv Zola of Brandeis University and the Boston Self-Help Center will supervise the project. I'd like to talk with you about this project as I intend for it to serve the disability movement in every way possible. Any guidance you can give me will be greatly appreciated.

I look forward to hearing from you. Things could get crazy here prior to my departure so I may take the liberty of giving you a call prior to my arrival in D.C.

Thanks again for the opportunity to learn and meet some good people. Give my love to Rita.

Sincerely,

Gene Williams
Gene Williams

P.S. I've enclosed a copy of a Peer Counseling handbook we're working on. Also, we would enjoy a copy of your keynote address.

NEW JERSEY DISABLED IN ACTION
P. O. Box 243
Paramus, New Jersey 07652

September 25, 1978

Dr. Frank G. Bowe, Director
American Coalition of Citizens With Disabilities
Room 817, 1346 Connecticut Avenue N.W.
Washington, DC 20036

Dear Frank:

It was a pleasure to meet you. I have heard many things about you and I was glad to discover these same nice things myself.

On behalf of the New Jersey Disabled In Action, I want to thank your organization for the invitation. It is evident that this was a well planned conference and much effort and patience were expended. The conference not only provided factual information but offered a spirit of cooperation and leadership. My only regret is that more people could not have attended.

Rita was not only a gracious hostess but a supportive colleague. Again, thank you. I look forward to working with you in the future.

Sincerely,

Diane Mutchler
President NJDIA

DM:fj
cc: George Chizmadia
Joe Owens

APPENDIX E

BIBLIOGRAPHY

Adams, Andrew. "Rehabilitation Consumerism: Confrontation or Communication and Cooperation?" *Journal of Rehabilitation*. Washington, D. C.: National Rehabilitation Association, January-February 1976.

Discusses the practical and philosophical underpinnings of the participation of disabled citizens in rehabilitation policy making. Adams examines how citizens' involvement can improve the service delivery system.

America Rehabilitation. Washington, D.C.: DHEW Rehabilitation Services Administration, July-August 1978.

Special issue on independent living. Reviews the history of independent living as a program goal and as a consumer movement. Articles examine independent living models in Massachusetts, Texas, California, and other states. It also features a legislative overview.

Arnstein, Sherry. "The Ladder of Citizen Participation," *AIP Journal*. July 1969.

Arnstein warns against tokenism and argues that the quality of citizen participation improves when the power of citizens to influence government programs increases. She draws examples from federal programs in urban renewal, anti-poverty, and Model Cities.

Bartels, Elmer. "Consumer Involvement in the Rehabilitation Process." Mimeo. Bedford, Massachusetts: National Paraplegia Foundation, (undated).

Bartels discusses the benefits of consumer involvement to the disabled community and to rehabilitation professionals. He proposes a definition of consumer involvement, and offers guidelines for effective participation models.

Bell, Daniel V. J. *Power, Influence and Authority*. Toronto: Oxford, University Press, 1975.

Bell examines these three concepts of political behavior from a communications perspective. His analysis is especially useful in describing the relationships between bureaucracies and consumer groups.

Birnbaum, Norman. Toward a Critical Sociology. London: Oxford University Press, 1973.

Birnbaum's reflections on man and bureaucracy challenge many of our democratic assumptions and serve as an interesting counterpoint to the work of Daniel Bell.

Blalock, Hubert H. An Introduction to Social Research. Englewood Cliffs: Prentice-Hall, 1970.

This basic text reviews many of the methodological problems involved in studying groups and public opinion. It provides a useful discussion of the role of participant observers studies in social research.

Bowe, Frank G. Handicapping America. New York: Harper and Row, 1978.

An intimate portrait of what disabled people face and feel. The book traces the struggle of disabled citizens and their families to eliminate barriers. It reviews the major judicial and political breakthroughs of the disability rights movement.

Bowe, Frank G. "On Severely Disabled Consumers and Rehabilitation." Remarks before the District of Columbia National Rehabilitation Association Conference, December 10, 1976. Mimeo.

Bowe summarizes the concerns of severely disabled individuals with respect to policy and client involvement, and points out the difference between legislatively mandated services and the services that are actually available. He offers suggestions for enhancing consumer involvement in rehabilitation.

Bowe, Frank G., Jacobi, Jan E., and Wiseman, Laurence D. Coalition Building. Washington, D.C.: American Coalition of Citizens with Disabilities, 1978.

A history and analysis of ACCD's efforts to design and implement a national model of communications and cooperation between self-advocacy, parent, and professional groups. The authors show that advocates of different disability groups can be brought together on key issues.

Bradford, Leland P. Making Meetings Work. La Jolia: University Associates, 1976.

This book, intended as "a guide for leaders and group members," examines the problems that emerge in all groups. Its chapters focus on leadership, interpersonal conflicts, and methods of promoting consensus. Bradford's work is based on the group dynamics theories developed by German psychologist Kurt Lewen.

Citizen Participation. Washington, D. C.: Community Services Administration, 1978.

Outlines theories and methods for increasing community involvement in publicly administered programs. The book also lists the citizen participation requirements within federal agencies.

Consumer Involvement: Rehabilitation Issues. Little Rock: Arkansas Rehabilitation Research and Training Center, University of Arkansas, June 1975.

This report begins by examining the federal regulations on policy consultation in VR programs. It then looks at the benefits and implications of consumer involvement in rehabilitation.

Cook, Terrence E. and Morgan, Patrick M. (eds.). Participatory Democracy. San Francisco: Canfield Press, 1971.

The introduction and readings give a comprehensive view of the history and philosophical controversies surrounding participatory democracy. Some of the authors argue that citizen participation is essential to keeping our society free and creative. Others insist that most community involvement plans offer only tokenism, never real power.

Engstrom, George A. "Research and Research Utilization -- A Many-Faceted Approach," *Rehabilitation Counseling Bulletin*. December, 1975.

> Research is now a major industry in America. Unfortunately, application of research innovations, particularly in the rehabilitation field, is sporadic. Engstrom discusses some of the ways researchers can ensure that the results of their studies will gain greater attention among practitioners.

Fay, Frederick A. "Housing Alternatives for Individuals with Spinal Cord Injury." Reprinted from *Selected Research Topics in Spinal Cord Injury in Rehabilitation*. Washington, D.C.: DHEW Rehabilitation Services Administration, Research and Training Centers Task Force Project, July, 1975.

> Fay describes the problems that persons with spinal cord injuries face when they try to find accessible housing. Two alternatives are discussed: total accessibility of all housing units, and accessible group residencies. The author encourages expanded partnerships between rehabilitation professionals and self-help groups.

Fay, Frederick A. "Consumers Respond to Results in Rehabilitation. Reprinted from *Rehabilitation and the Measurement of its Results*. Washington, D.C.: Commission on Accreditation of Rehabilitation Facilities, 1973.

> Demonstrates how disabled self-advocates can play major roles in the planning, delivery and evaluation of rehabilitation services. The author stresses that providers should work *with*, rather than *for*, disabled persons.

Fiorito, Eunice K. "Advocacy and Constituent Relations." Washington, D. C.: DHEW Rehabilitation Services Administration, (undated).

> Fiorito's paper presents an overview of the traditional relationship between disabled citizens and rehabilitation providers. Often this relationship has fostered dependence among disabled citizens and paternalism among providers. Fiorito notes the new activism within the disabled community, and outlines the steps government must take to utilize the resources of the community and to improve service delivery systems.

Groenning, Sven, Kelly, E. W., and Leiserson, Michael. *The Study of Coalition Behavior: Theoretical Perspectives and Case Studies from Four Continents*. New York: Holt, Rinehart and Winston, 1970.

Especially valuable for its case studies, this collection of essays examines how coalitions are formed and maintained.

Hubbard, J. C., et. al. "Mass Media Influences on Public Conceptions of Social Problems," *Social Problems*. October 1975.

Explores the various stages in the evolution of social problems, from their emergence through their legitimization and finally to their institutionalization. Hubbard describes how bureaucracies and interest groups form around an issue and help to shape it.

Katz, Elihu and Danet, Brenda (eds.). *Bureaucracy and the Public*. New York: Basic Books, 1973.

The book represents one of the first efforts to collect articles on the factors that influence relationships between bureaucrats and clients.

Kelly, E. W. "Techniques of Studying Coalition Formation," *Midwest Journal of Political Science*. Vol. 12, 1968.

Kelly describes four characteristics of an on-going, effective coalition.

Kleyman, Paul. *Senior Power: Growing Old Rebelliously*. San Francisco: Glide Publications, 1974.

Kleyman traces the history of advocacy in the senior power movement. Although it focuses on one activist group in San Francisco, the author stresses that the broader the viewpoint of issues and constituencies, the more effective and practical the politics.

Krause, Elliot. "Functions of a Bureaucratic Ideology: 'Citizen Participation'," *Participatory Democracy*. Cook, Terrence E. and Morgan, Patrick M. (eds.). San Francisco: Canfield Press, 1971.

Argues that the chief beneficiaries of citizen participation plans are the bureaucrats themselves. Krause says that community involvement models do not give any real power to the citizenry but do serve to give the decisions of administrators a cloak of legitimacy.

Lehnen, Robert G. American Institutions, Political Opinion and Public Policy. Hinsdale: Dryden Press, 1970.

Gives an excellent discussion of the concept of "attentive publics." Lehnen notes that citizen involvement in public affairs is limited and selective. Some individuals do not take an interest in any public issues, while others are highly active and seek a role in various matters. There are, however, individuals who follow and focus on one particular set of issues and help determine how they will be discussed.

Mitrany, David. The Functional Theory of Politics. London: St. Martin's Press, 1976.

Mitrany is the founder of the "functionalist school" of political science. His assertion that groups come together through "the experience of rewarding common activity" served as one of the conceptual foundations for plans to create a European Community.

National Health Council, Inc. "Consumer Input -- Why?" Mimeo. (undated).

The article presents six practical and philosophical reasons for consumer input into health services planning and action. It emphasizes cooperative decision-making by health service providers and consumers. The article is representative of the impact of consumerism on the health services field.

National Summary of Client Assistance Projects Annual Reports. Washington, D.C.: DHEW Rehabilitation Services Administration, March 1978.

Discusses the impact of the Client Assistance Projects (CAP's) around the country. The report notes that although some VR counselors indicated initial anxiety over the idea of having an ombudsman serve as a facilitator between clients and agencies, the CAP's have improved services, led to greater client satisfaction, and won the endorsement of VR personnel.

Neufeld, G. R. "Advocacy: An Examination of its Interaction with the Human Services Delivery System," Advocacy Systems for the Developmentally Disabled. Bensberg, Gerald J., et al. (eds.). Lubbock: Texas Tech University Press, 1976.

Neufeld describes the maze of agencies that disabled persons and their families face when they try to get services. He argues there is a need to have advocates who can help cut through that maze.

"Policy Development Consultation," *Rehabilitation Services Manual*, Chapter 25. Program Regulation Guide RSA-PRG-76-7. Washington, D.C.: DHEW Rehabilitation Services Administration, September 1975.

Chapter 25 requires all state VR agencies to develop and submit a plan showing how they will solicit and respond to the views of clients and others interested in rehabilitation. Though Chapter 25 does not specify any model for consumer involvement, it does say that the plan must offer the chance for meaningful participation in policy making and service delivery.

Polling Magazine. New York: funded by the DHEW Office of Developmental Disabilities, Fall, 1976.

This issue of *Polling Magazine* emphasizes that persons with developmental disabilities should be involved in shaping the decisions that will affect their lives. The *Magazine* echoed the growingly assertive voice of disabled citizens struggling for self-determination -- struggling to define themselves.

Rehfuss, John. *Public Administration and Political Process*. New York: Charles Scribners and Sons, 1973.

Rehfuss explores the essentially political nature of bureaucratic decisions. He suggests that the relationship between bureaucratic and consumer/client is shaped by a range of factors, including the political power of the client or his representatives.

Remmes, Harold S. *Consumer Advocacy: State of the Art.* Funded by DHEW Rehabilitation Services Administration. Grant No. 16-P-57856/1-01.

This work reports on a consumer leadership conference held in April 1975. The conference, an advocacy project sponsored by the Massachusetts Council of Organizations of the Handicapped and by Tufts Rehabilitation Research and Training Center, brought together disabled self-advocacy leaders from across the country.

Remmes, Harold S. *A Consumer's Guide to Organizing the Handicapped*. Hyde Park: Massachusetts Council of Organizations of the Handicapped, (undated). Funded by DHEW, Grant No. 16-P-65800/1-08.

This excellent and readable work brings together the experience of more than twenty member groups of the Massachusetts Council of Organizations of the Handicapped and provides a tool for consumers who want to develop cohesive organizations. The book recommends alignment with the American Coalition of Citizens with Disabilities.

Riker, William. The Theory of Political Coalitions. New Haven: Yale University Press, 1962.

A basic introduction to the theoretical aspects of coalition building, this book examines the ways interest groups come together and develop a framework for joint action. Riker also explores the instability of political coalitions.

Shulman, Robert. "The Normalization Principle and its Implications for Residential Services for the Mentally Retarded." Mimeo. Department of Educational Psychology, New York University, Fall, 1974.

This paper traces the attitudes of society toward "deviants" and discusses the emerging principle of normalization of human services for mentally retarded persons in the United States. It stresses the need to have citizen advocates who can safeguard the rights of mentally impaired persons.

Silvert, Kalman H. Man's Power. New York: Viking Press, 1970.

Silvert analyzes the factors that shape people's political behavior. He looks at values, money, ethnic ties, and a host of other variables. This work is girded on the belief that individuals are not puppets, but rather creative, self-conscious beings who can and do design their environment.

Stearns, James C. "Crutch Power." Reprinted in Hearings on H.R. 8395, Senate Committee on Labor and Public Welfare, Subcommittee on the Handicapped. 92 Congress, second session, part 1, 1972.

The paper discussed the need for disabled people to unite and become their own advocates. Stearns also sheds much light on the political history of the rehabilitation legislation that Congress was debating in 1972.

Stewart, Larry, (ed.). *Perspective in Education of the Deaf: Proceedings of the National Forum V, Council of Organizations Serving the Deaf*. DHEW Rehabilitation Services Administration, 1972.

Discusses how effective leadership and involvement of deaf professionals and self-advocates can strengthen educational services.

Thoben, Patricia J. "Civil Rights and Employment of the Severely Handicapped," *Rehabilitation Counseling Bulletin*. Journal of the American Rehabilitation Counseling Association, June 1975.

Argues that architectural barriers, inadequate transportation, and employer bias severely limit the job options of disabled people. Thoben discusses how the civil rights movement among disabled citizens has helped to highlight these barriers. She also discusses the anti-discrimination provisions in the Rehabilitation Act of 1973 (P.L. 93-112).

Thursz, Daniel. "Consumer Involvement in Rehabilitation," *Rehabilitation Record*. Washington, D. C.: DHEW Rehabilitation Services Administration, September-October 1969.

Dr. Thursz' remarks appeared in a special issue of *Rehabilitation Record* that reported on the National Citizens Conference on Rehabilitation of the Disabled and Disadvantaged, held in June 1969. He warned that unless disabled people were given a meaningful voice in decision-making and new career opportunities in the service delivery system, they would continue seeing that system as an uncaring, ineffective bureaucracy.

Varela, Rita A. "Self-Advocacy and Changing Attitudes," *Public Awareness Viewpoints*. Richman, Gary and Trohanis, Pascal (eds.). Chapel Hill: Developmental Disabilities Technical Assistance System, University of North Carolina, Spring 1978.

Reviews how telethons and public service announcements have depicted disabled people, and argues that self-advocates must be consulted and involved whenever agencies embark on community awareness campaigns.

Vocational Rehabilitation Manual, Chapter V. Washington, D.C.: March 25, 1949.

This Chapter, which has been replaced by Chapter 25, envisioned advisory committees as public relations

vehicles for VR agencies. The difference between this Chapter and the mandate of Chapter 25 is striking.

White House Conference on Handicapped Individuals Final Report, Vol. 2, Part A. Washington, D. C.: DHEW Rehabilitation Services Administration, 1977.

This historic document reflects the views of hundreds of disabled persons, parents, and rehabilitation providers. Delegates to the White House Conference were chosen in meetings and caucuses held throughout the country. The volume also contains a minority report which reveals many of the attitudes of the militant sector of the disabled self-advocacy movement.